
**An evaluation of the information needs of people
with adolescent idiopathic scoliosis at the point of
first diagnosis at the hospital clinic:
Final Report**

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Authors

Dr Josette Betany-Saltikov, Shaun Wellburn, Pat Watson, Dr Lisa Arai, Emma Robinson, Dr Sharon Hamilton.

School of Health & Social Care

This report was prepared by a team of researchers from Teesside University.

Address: University of Teesside, Health and Social Care Institute, Parkside West
Offices, Middlesbrough, UK, TS1 3BA.

Tel: +44 (0) 1642 342967

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Executive Summary

Background: The Patients Charter (1992) clearly states that patients` have a right to information about their condition. In patients with Adolescent Idiopathic Scoliosis very little is known about the information provided to patients and their families as well as the information needs of service users. Failure to fully address patients` and their families` health information requirements can lead to significant stress and anxiety.

Objectives: This research was commissioned by the British Scoliosis Research Foundation to evaluate patients` information needs at the first point of diagnosis with adolescent idiopathic scoliosis at hospital (AIS).

Design of the research study: A mixed methods approach was used and comprised six independent studies which address the same major aim. Together the studies present a holistic picture of the information needs of people with AIS.

Methods: This report includes a literature review, interviews conducted with patients at one Centre in the North East of England and supplemented by a national survey of UK clients with AIS, a survey of UK NHS Consultants, an analysis of information contained on Websites recommended by UK surgeons to patients, and a content analysis of a sample of UK hospital materials currently provided to patients.

Results: Both parents and young people identified a need for additional information. It was clear that verbal information alone was not sufficient to address that need. The findings from the study also supported the need for access to information in the period between GP referral and the visit to the consultant. There is also a view that general posters and leaflets on scoliosis should be available at GP surgeries as a way of raising general awareness of the condition. Furthermore it was suggested that awareness of the condition should be improved within school environments.

There is a need for all information to be user friendly and in a language that is easily understandable. Separate information packs using different formats for parents and young people are felt to be more beneficial in addressing the information needs of both groups. Young people also felt that some guidance on how to talk about their condition, and what it means, with their friends was important as many did not know how to do this. The opportunity to communicate with others suffering from AIS, listen to their experiences and to learn from each other was felt to be an important step forward in meeting the information needs of young people.

Conclusions: AIS is a life-changing diagnosis for young people and their families. Patients and families have a need for good quality information at the point of diagnosis so they are able to make informed choices about their treatment. Currently the quality and range of information available is inadequate and needs to be strengthened.

Introduction

The word `information` is derived from the Latin or Italian term `*informare*` which literally means to "give form to". The origin or etymology of this word therefore connotes `an imposition of structure upon some undetermined mass` (Allan & Selander 1985). Most people tend to think of information as disjointed little bundles of "facts". However the Oxford dictionary defines the word as being connected to knowledge, as well as to communication. `*Knowledge communicated concerning some particular fact, subject or event; that of which one is apprised or told; intelligence, news*`. In other words the way the word `information` is used can refer to both "facts" in themselves as well as the *transmission* of the facts.

Seeking Information

Seeking these `facts` or information by patients is considered to be a process of sense-making whilst an individual is forming a personal point of view (Dervin, 1983). Uncertainty and anxiety are cited as being an integral part of this process, particularly at the initial stage of learning (Kuhlthau, 1991). Reportedly, there are a wealth of leaflets and booklets available on health education, including the management and treatment of various diseases (Arthur 1995). However, failure to fully address patients' and their families' health information requirements is consistently noted in the literature across different health conditions (Houston *et al.* 2000, Rahi *et al.* 2003). This is an important area for research as more complex conditions such as scoliosis which have an idiosyncratic nature and progression may require a more integrated approach to help allay service users associated fears and apprehension.

Adolescent idiopathic scoliosis

The term scoliosis is derived from the Greek word for curvature and is used to describe a three-dimensional deformity that typically consists of deformation of the lordotic and kyphotic curves in the sagittal plane, lateral curvatures developing in the frontal plane and vertebral rotation in the transverse plane (Kouwenhoven & Castelein 2008, Veldhuizen *et al.* 2000, Wright 1997). Scoliosis is defined as a lateral curvature of the spine greater than ten degrees (Kane 1977); this is usually measured using the Cobb (1948) method on a standing anteroposterior radiograph.

There are many different types of scoliosis with clearly defined aetiologies such as, neuropathic (due to disease or anomaly of the nerve tissue), myopathic (due to disease or anomaly of the musculature) or congenital (due to congenital anomalies of the vertebrae) (Cailliet 1975). In the most common type of scoliosis, which accounts for 70-80% of cases (Rowe 2003, Riseborough & Wynne-Davies 1973), in spite of a great deal of clinical and epidemiological research the aetiopathogenesis remains unknown and as such is referred to as idiopathic (Burwell 2003, Lowe *et al.* 2000).

Idiopathic scoliosis can in turn be sub-divided into three categories depending on the age at onset: infantile when curves develop before the patient is three years old, juvenile when curves develop between the ages of four and nine years old and adolescent when curves develop between the ages of ten and the end of growth (James 1954). Infantile and juvenile scoliosis account for around 1% and 12-21% of cases respectively meaning AIS is the most commonly occurring form of the condition (Dobbs & Weinstein 1999).

Reported rates of prevalence of AIS in the literature vary between 1 and 4% of the at-risk population (Parent *et al.* 2005, Roach 1999, Kesling & Reinker 1997, Kane 1977), although rates as high as 9.2% have also been reported (Nissinen *et al.* 1993). The rate of prevalence is also strongly related to gender, whilst an equal distribution exists between males and females for curves around 10 degrees the ratio is suggested to be 5.4 girls to 1 boy for curves over 20 degrees and as high as 10:1 girls to boys in curves greater than 30 degrees (Roach 1999, Rogala *et al.* 1978). The treatment pathways for AIS vary internationally. For mild curves (i.e. less than 25 degrees) watchful waiting (observation), followed by bracing if the curve progresses beyond 25 degrees, is the typical treatment option in the UK and North America. In some countries curve specific exercises and physical therapy is recommended, mostly by European clinicians (Weiss 2006, Negrini 2005) for these types of mild curves with low risk of progression. The aim of specific physical therapy in the treatment of AIS is to reduce the potential for progression of the condition in mild curves (up to 25 degrees) and to enhance the effect of a brace and offset the side effects of bracing in moderate curves (25-45 degrees) (Weinstein 2008).

The anticipated outcome of bracing is to prevent progression of the curve until the patient reaches skeletal maturity, at which time the risk of progression of the curve (and subsequent surgical intervention) is significantly reduced. There is much debate as to the efficacy of the use of scoliosis-specific physical therapy exercises in the treatment of AIS and their effectiveness; a Cochrane review by Romano *et al.* (2010) is currently being conducted on the current evidence. Similarly a Cochrane review by Negrini *et al.* (2010) on the effectiveness of bracing in the treatment of AIS

found that there was very-low quality evidence in favour of bracing, and that patients and parents should discuss treatment options with their treatment providers.

The generally agreed indicator for surgical intervention is a primary curve with a Cobb angle greater than 45 to 50 degrees (Bridwell 1999, Kostuik 1990). Surgery involves the use of instrumentation to straighten and fuse the spine. The instrumentation used in surgery comes in a variety of forms (hooks, rods, wires, screws) and is typically administered using a posterior approach, although an anterior approach is also used. The adverse effects of surgery are primarily the loss of spinal motion; whilst potential complications include non-union, infection, back pain and paraplegia (Bridwell 2007). Accordingly, the treatment process for AIS whether it is operative or non-operative involves major decisions, anxiety and stress for patients and their families.

Summary

Information sources for patients with chronic health conditions such as cancer, diabetes and coronary heart disease are plentiful. However, a preliminary review of the literature regarding scoliosis did not find any studies that have investigated the information needs of patients and their families at the first point of diagnosis at the hospital clinic. This is a major gap in the literature. Consequently, this study identifies new knowledge in this field. The findings will enable specific information needs to be identified and recommendations to be made for the production of information materials for these patients and their families.

This report presents the findings from an evaluation of the information needs of people with AIS at the first point of diagnosis at the hospital clinic and is presented in five sections. The first section explores the literature underpinning the concepts around patient information and places the study within the policy context of patient involvement in the management of their own healthcare. The following four sections outline the findings from the empirical work undertaken which comprise: interviews conducted with patients at one centre in the North East of England, supplemented by a national survey of UK clients with AIS, a survey of UK NHS consultants; information contained on Websites recommended by UK surgeons to patients, and a content analysis of a sample of UK hospital materials currently provided to patients.

Background Literature

Patient involvement and consultation regarding the management of their own health care has been on the political agenda in the UK for a number of years (Le Var 2002). Indeed the need for information by patients managed in the National Health Service (NHS) has seen a dramatic rise in the last two decades. As far back as 1989 the Department of Health (DoH) stated that hospitals should offer explanations not only of patients' illnesses but also of their proposed treatments. In 1992 this view was reinforced by 'The Patients Charter' which clearly states the right of patients' to information about their condition. This was followed in 1997 by a statement from the NHS Executive (1997) which articulated the necessity for health-care professionals to actively involve and encourage patients to participate in any decisions about their health. The DoH (2008) paper 'High Quality Care for All' called for the improvement of patient care through staff development of communicative partnerships.

What do patients consider to be the areas of greatest importance?

The areas of care that patients considered being of the greatest importance was highlighted in a survey conducted by the Picker Institute in England (Boyd 2007). The results of this survey recommended that a high priority should be placed upon communication, patient-professional interactions and treating patients as individuals to be reflective of a truly patient-centred healthcare system.

Changing models of care and shared decision making

Historically, a paternalistic model of care was the 'norm', with health care professionals typically assuming responsibility for making treatment decisions on behalf of patients that were in the patients' best interests. Nonetheless, in recent

years beneficence, or actions that promote the well-being of others, is no longer the case and patient-autonomy through participation in decision-making is now considered to be of the utmost importance (Pellisé & Sell 2009, Deber 1994). According to Deber, (1994), a minority of families seek either complete control of their treatment or abdicate treatment decisions to their physician. Therefore, it is considered a prerequisite that patients' and their families receive as much detailed information about their condition from their clinicians, to augment effective decision making (MacCulloch *et al.* 2009).

As mentioned previously the Department of Health's (DoH), Patients' Charter, states that every citizen has the right to a clear explanation of any proposed treatment before they agree to treatment (DoH 1992). Shared decision making, in which patients and health professionals participate in both the process and ownership of decision making has attracted considerable interest as a means by which patients' preferences can be incorporated into clinical, evidence-based decision making (Coulter 1997).

An example of shared decision making can be seen in The Expert Patient Programme (DOH 2001). This was developed to support people living with long term conditions in the self-management of their condition. The programme focussed on the development of five core self-management skills, key factors of which were knowledge and patient education. The paper describes the expert patient as,

- One who feels confident and in control of their lives.
- Aims to manage their condition and its treatment in partnership with health care professionals

- Communicates effectively with professionals and are willing to share responsibility and treatment
- Are realistic about the impact of their disease on themselves and their family
- Uses their skills and knowledge to lead full lives

Ensuring that the patient has pertinent Information is crucial for achieving these aims and supporting the empowerment of patients.

The need for patients to be well informed

Information is vital to patient decision-making. Pellisé and Sell (2009) suggest that patients should be informed of the nature of outcomes as well as the risks and benefits of procedures and treatments in order to enable them to make informed decisions. Coulter *et al.* (1999) however, make the point that consultation times are limited; consequently, there is often inadequate time to fully explain a particular condition and relevant treatment choices. In addition, it is reported that on average, a patient forgets half of what they are told within five minutes of leaving the consultation room (Treweek *et al.* 2002). The findings of a study conducted by van Schaik *et al.* (2007) support the suggestions of Coulter *et al.* (1999) and Treweek *et al.* (2002). The study found, from an evaluation of postal questionnaires returned by 106 scoliosis patients and their families, that respondents lacked knowledge about their condition. Ninety per cent of participants reported their knowledge of scoliosis-related topics as average or poor. It may therefore be inferred that in reality, consultations may not be as effective as would be preferred.

Information exchange contributes to enhanced patient perceptions

Shaw & Wilson (2009) suggest that the exchange of information and good communication can contribute to enhanced perceptions by patients of high-quality care and improve overall satisfaction of healthcare services. Indeed work by Legg-England & Evans (1992) found that hypertensive patients benefitted if they adopted an active role in treatment. Similarly Kaplan *et al.* (1989) found that patients involved in discussions about the management of their diabetes achieved better sugar control, a caveat to this being that the pathologies reported were such that patients could modify their diet and lifestyle to instigate a positive change.

Patients need to understand the information and find it useful and acceptable

Information provided to patients whether it be paper based or web based needs to be both acceptable and comprehensible to patients (adults and children) and also needs to contain scientifically reliable information based on the best and most up to date information (Coulter *et al.* 1999). Misunderstanding of information can lead to patient anxiety (Dey 2004) and Weisbord *et al.* (1997) go so far as to suggest that misinformation could be a matter of life and death in certain circumstances.

Similarly Boyd (1987) emphasises the importance of ensuring that the content of patient information materials is up to date, accurate and contains not only what patients *need* to know but also what they *want* to know. Also for patient support to be effective patients must be able to ask for any information that has not been offered to them or if they do not understand any information to be able to ask for explanations (Wilson *et al.* 2009). This is highlighted in the National Patient Safety

Agency (NPSA) '*Please ask*' campaign in 2006 which aimed to make people more active in their health care.

Verbal versus written information

If health clinicians are to inform their patients fully, written information is an area which should be more comprehensively researched for ethical, quality and economic reasons (Arthur, 1995). Further, for patients to express informed preferences, it is paramount they are afforded detailed information about their condition and the likely outcomes with and without treatment (Coulter *et al.* 1999).

Arthur (1995) conducted a literature review to examine written patient information focusing on readability, recall, communication, compliance and patient satisfaction in the context of chronic disease (Arthur 1995). From the review, it was suggested that an educational program including written information backed up with verbal information may be conducive for patient learning and recall (Lorig *et al.* 1987).

The need for patients to have access to written material has been highlighted by Pellisé and Sell (2009) both to be used in discussions with health professionals and also to retain as a tool for reference purposes. A study conducted by Gauld (1981) compared the effects of written and verbal advice against verbal advice only. It was found at follow-up that the patients who were exposed to the amalgamation of written and verbal advice had an increased capability to recall the information than those who were given verbal advice only. Sloan (1984) found that vast quantities of leaflets and booklets on health education as well as the management of various health conditions were available. However a study by Donovan & Blake (1992) revealed

that despite the large quantity of existing materials patients were still not satisfied. Arthur (1995) recognises that relatively few studies have been carried out to evaluate this flood of information. Thus it could be interpreted that patients are not being provided with comprehensible and tailored information that satisfy their information needs. This view, that patients and their family's information needs are failing to be addressed, is well supported in the literature (Houston *et al.* 2000, Rahi *et al.* 2003).

Web based materials

An alternative source of written information is that which is presented electronically via the Internet. The internet is a rapidly expanding communication network with an estimated 765 million users worldwide in 2005 (Mathur *et al.* 2005). Correspondingly, medical information is a common enquiry on the web with in excess of 100 million Americans reportedly making hits for medical information in 2000 (Mathur *et al.* 2005). The development of the World Wide Web has seen the volume of freely available information increase enormously (Wyatt 2000, Golladay *et al.* 1998). It is reported in the literature that medical information is one of the most common forms of enquiry on the Internet (Mathur *et al.* 2005). However the unregulated format of the Internet and the availability of Web server software mean that anyone can set up a Website and publish health related information that is available to everyone. The problem then becomes assessing the reliability and credibility of the information, rather than being able to find information on a particular condition in the first place (Pellisé & Sell 2009).

In 2002, Eysenbach & Kohler conducted a qualitative study using focus groups to identify the techniques used by consumers when searching for health information on

the net (n=27, mean age 37). The researchers conducted semi-structured interviews with the participants immediately after their search to elicit the decision-making process and criteria for selection of the website. The important emerging themes from their results showed that generally the participants did not pay attention to the origin of the material retrieved (for example government agency or less reputable source).

In all cases cited, the reason for this failure was not that the Website did not disclose its source, rather that the users did not seek the information (Eysenbach & Kohler, 2002). This could be a potential issue for the patient and medical staff, as an eagerness for medical knowledge can lead the individual to unregulated sites, and thereafter overrides the individual's ability to question and subsequently dismiss unsubstantiated medical facts. Unfortunately, the enormity of the Internet makes regulation of all Websites virtually impossible.

A later article by Mathur *et al.* (2005), involved three orthopaedic surgeons who evaluated the quality and accuracy of information on fifty scoliosis Websites. Their findings somewhat supported those of Eysenbach & Kohler, in as much as the majority of Websites (44% of which were academic and for health professionals), had poor content, quality and accuracy (Mathur *et al.* 2005).

Quality of information

Recently there have been a number of studies carried out that have assessed the quality of information relating to a variety of health conditions (Kunst *et al.* 2002, Meric *et al.* 2002, Li *et al.* 2001, Impicciatore *et al.* 1997). These studies found the

Web based information they analysed to be inadequate. Similarly a review of 50 Websites, identified through a search for the word 'scoliosis' entered into five search engines, conducted by Mathur *et al.* (2005) concluded that the information on the Internet about scoliosis is poor. However this review did not use a validated instrument to evaluate these web sites, instead they used a series of disease specific keywords on an ordinal scale so the value of the results remains unclear. Clearly there exists a gap for the information needs of patients themselves to be identified and for information materials produced to be based on addressing these needs. It would seem sensible that where health professionals recommend Websites to patients as a source of information, those Websites need to have been previously evaluated as both reliable and valid.

Information needs to be tailored to patients' needs

The diagnosis of AIS can occur at any time between the ages of 10 and 18 years of age (Schwab *et al.* 2005, Morais *et al.* 1985, Brooks *et al.* 1975) and also at varying stages of progression of the condition (Beauséjour *et al.* 2007, Fazal & Edgar 2006). Because the condition affects such a broad age group and can be diagnosed at various stages of the condition, the information needs of these patients can be quite disparate. This then implies that there is a requirement for materials designed for the purpose of informing and educating patients and their families to be tailored to suit individual needs, a view which is supported by Vaidyanathan *et al.* (2001).

Clearly, there is a requirement for written and verbal information to not only be clearly written and age specific, it also needs to be tailored selectively for this diverse age range. For example, information for a child would need to be simplistic with

pictures. It was reported by Coulter and colleagues that the use of pictures and diagrams was appreciated by the patient. However, they did not like “gory” or “scary” pictures which can be found very frequently in numerous scoliosis Websites, particularly those showing the effects of surgery (Coulter *et al.* 1999).

In contrast, a young adult’s explanation of options and outcomes may require a more comprehensive vocabulary. Depending on the patient’s age, socioeconomic background, individual fears, concerns and understanding may vary dramatically between patients regardless of age. Anderson & Armstead (1995) cited that a relationship between socioeconomic status and health has existed for some time with better health outcomes generally found in the higher socioeconomic groups.

This requirement concurs with later research by Mordiffi *et al.* (2003), in which it is stated that training for health care professionals must target ‘the changing of the mindset’ of health care practitioners from a paternalistic to a transactional approach in the communication process. An explanation of this statement may well be that the attending medical staff decides how much information the patient needs due to time constraints or possible lack of insight of the patients’ own desire for knowledge. Further, the important role of the multidisciplinary team, (MDT), was alluded to, as this may provide more comprehensible literature (Maycock, 1991).

‘Like’ to know versus ‘need’ to know

Communication is a two way process, and it is important to discover what information patients would like to know (Boyd, 1987). Equally, it is also essential to inform patients of what they need to know (Donovan & Blake, 1992). A study by

Coulter *et al.* (1999) examined information materials provided to patients for a range of conditions. The study found that in all but a few cases, patients' information needs had not been researched **before** the materials had been produced. This lack of research to identify their information needs was suggested as the cause of a number of important omissions identified during the review of the materials. Hence in order that information materials can be effectively created, the information needs as defined by the patients themselves, must be identified (Coulter *et al.* 1999).

Implications for the study

Government policy very much supports the notion of patient participation and shared decision-making in the management of health conditions. However, it is clear that patients cannot express informed preferences unless they are given sufficient and appropriate information on their condition and likely prognosis with and without treatment (Coulter *et al.* 1999). Therefore it is vital that appropriate and high quality information is made available for scoliosis patients and their carers.

Although vast quantities of information are available to patients, research by Donovan & Blake (1992) revealed that patients would like more written information (Donovan & Blake, 1992). This questions the value of the currently available literature. Consequently what needs to be considered from the aforementioned finding is what information the patient and involved family members require, and in which format the information would be best delivered. The old adage 'a picture paints a thousand words' may be representative of the ideal. However, the specific information, required depth of detail, specific format, verbal, written or pictorial or a combination of all three remains unsubstantiated and equivocal.

Design of the research study

This research study comprises six independent studies which address the same major aim: to evaluate patients' information needs at the first point of diagnosis with AIS at hospital, and together present a holistic picture of the information needs of people with AIS.

1. A literature review of published literature on patient information needs of adolescents with idiopathic scoliosis and their parents.
2. Semi-structured interviews with service users at the point of first diagnosis
3. An on-line survey to service users (patients and their families).
4. An e-mail survey to consultants in 20 major scoliosis centers in the UK to enquire about information given to people at their first discussion about idiopathic scoliosis.
5. A Website analysis to examine, for quality and reliability, the information content of Websites that are suggested by clinicians to AIS patients and their parents attending specialist scoliosis centres in the UK.
6. A content analysis to compare the available information at NHS hospital scoliosis clinics with the information needs of adolescent service users and their parents

Overall aim

To evaluate patients' information needs at the first point of diagnosis with AIS at hospital.

Overall objectives

- To gain an understanding of the range of information needs of people with adolescent idiopathic scoliosis (and their parents) at the point of first diagnosis.
- To evaluate NHS surgeons' understanding of the needs of patients with AIS and their parents at the first point of diagnosis.
- To evaluate the content of information of web-sites recommended to AIS patients and their parents by NHS scoliosis consultants in the UK
- To evaluate the content of information offered by major scoliosis clinics in the UK.

Local and national perspectives of the information needs of people with Adolescent Idiopathic Scoliosis at the first point of diagnosis: Patient interviews and surveys

Aim

The aim of this study was to identify the information needs of patients and their families at the point of first diagnosis of AIS in hospital clinics.

Secondary aims were to explore perceptions of the information that is available and was provided to them at the point of first diagnosis. Furthermore to investigate potential improvements in terms of both content and mode of provision of information that would better meet the needs of both AIS patients and their families.

Methods

A multi method approach was adopted which included:

- Semi structured interviews with patients at a local centre (James Cook University Hospital)
- An online questionnaire placed on the Scoliosis Association UK (SAUK) Web site

In total, twelve paired interviews were carried out with adolescent patients and their parent/carer(s) visiting the scoliosis clinic at James Cook University Hospital (JCUH) (Appendix 1 – Interview Schedule). The time since diagnosis among participants varied and included some who had recently been diagnosed, some who had been diagnosed within the last two years and others who were seeing the consultant for the first time and awaiting full diagnosis. These interviews provided a local perspective on the information needs of AIS patients and their families.

All qualitative data were coded using the NVivo 9 qualitative data package. A thematic analysis approach was used to draw key themes from the data.

This section of the report brought together local findings from the interviews and national findings from the online questionnaires. Inferences were drawn as to the effectiveness and availability of current information, experiences of diagnosis, information needs and ideas for improving information sources to meet the needs of patients and their families at the point of first diagnosis of AIS.

Local Perspective: Patient and parent interviews

Demographics

In total, 12 paired interviews were completed with adolescents and parent/carer(s) presenting at the scoliosis clinic at JCUH. Interviews were carried out over a five month period. Interview participants were at differing periods of time since first diagnosis, with some attending clinic for the first time, others recently diagnosed (within the past year) and others who had been diagnosed for longer than one year.

Of the 12 participants, ten were female and two were male. The age range was 12-16 years old. Participants were at varying stages of progression of the condition ranging from mild, requiring no immediate treatment, to the more severe, requiring surgical intervention.

Awareness prior to diagnosis

Awareness of AIS prior to diagnosis among participants varied. Those participants reporting a family history of scoliosis were more aware of the condition, of what to

look for but generally had less knowledge of progression, treatments and effects. Generally participants not reporting any family history of the condition portrayed very low awareness of the condition.

It was also noted that although the literature fails to fully establish scoliosis as being hereditary, that 4 of the 12 respondents (33%) report other family members as having scoliosis and in some cases more than one family member.

Respondents reported difficulties in accessing information in the period between initial visit to their GP and diagnosis by a consultant. There was a general view that GPs offered little information and that there was no written information available through the GP surgeries to prepare them for diagnosis.

Personal Experiences of Diagnosis

Initial Identification

This study highlighted that parents were often delayed in identifying issues with their child's back. Some parents reported that young people today generally expect higher levels of privacy and spend a lot of time in their rooms alone or with friends. Parents acknowledged that unless the young person is experiencing pain warranting them to inspect their child's back, then identifying the onset of any curvature is less likely.

One parent stated:

I saw it once just when she was washing her hair over the bath or something and I was in there and I just thought oh when she bent over you know the back isn't symmetrical. (Interview 1)

Another parent stated:

I happened to notice it when she wore a tight fitted dress, she put it on and I said to her that for some reason that hip is up so we automatically thought one leg was longer than the other so went to the doctor. (Interview 6)

Whereas in the past, screening programmes existed within schools to identify scoliosis, there are currently no scheduled checks for the condition in children. This places responsibility for early detection primarily with parents or the young people themselves. Given the general lack of awareness and a young person's desire for privacy making identification difficult, there is some argument to support checks by health professionals.

In a number of cases initial identification was provided by a GP as a result of a visit to address physical pain either in the back, shoulders or hips. Prior to this visit no previous link had been made to scoliosis by either the child or the parents. For some, this resulted in a need for further knowledge as information provided by the GP varied. This resulted in many turning to the Internet to access more information as a way of better understanding the condition and in preparation for a consultant referral. The role of the Internet is discussed in more detail later in this report.

Response to Diagnosis

Respondents reported a range of emotions following diagnosis at the clinic. The reaction to actual diagnosis from the patients was generally one of acceptance or devastation. Some reported feeling upset, most adopted an attitude of "I will deal with it". It could be argued that this approach was due to the natural resilience of

some young people to adapt to given situations. Although the lack of awareness and understanding of the condition and its impact on their future lives both in the long and short term could also be a factor.

Comments from the young people included:

It was a bit of a shock. (Interview 11)

I wasn't shocked because I knew a friend that had it and her case wasn't very major. I didn't really know much about it so I just thought it was something that quite a lot of people have. (Interview 10)

Well it didn't really seem that it was that serious because I guess that I wasn't in that much pain so it didn't seem that bad so I wasn't that worried about it but there was still a bit of nervousness and anxiety at the back of my mind.
(Interview 2)

One parent went on to state that at first her daughter was:

. . . beside herself, she didn't want to go out, she didn't want to see friends or anything like that. (Interview 1)

Very few of the young people involved in this study voiced concerns for the future at the time of diagnosis. For the young people it would appear that the point of first diagnosis is not the best time to be bombarded with information as both they and their parents need time to come to terms with the diagnosis and think about what information they require.

Early concerns raised by the young people themselves largely focused on those requiring surgery. Although no real concerns were raised about the operation itself, the impact of the surgery raised concerns with time lost from school and impact on schoolwork, particularly for those involved in GCSE coursework and exams and also the immediacy of surgery and resultant scarring. Parent reactions were generally of shock and concern for the future.

Comments included:

I was devastated. (Interview 1)

When we were first diagnosed it just hit me so hard that I actually left the hospital in sort of a, how can I put it, you know in shock. I didn't even know there was such a condition, it was the first time I had ever heard of it.
(Interview 4)

I was quite surprised because there's no history of it in our family. I didn't know much about it and was really worried about the future because they were saying she may need an operation or may not and it was kind of hanging over us. (Interview 5)

Parents reported a need for more information at the point of diagnosis and were more likely to go and seek out information from other sources on leaving the hospital. They highlighted early concerns about surgery and the impact of AIS in the longer term on their child.

Some parents reported some frustration at the delays in diagnosis and misdiagnosis of the condition in the early stages. Some children had not been referred for consultation for over 2 years after first contact with a GP as their GP had misdiagnosed and failed to refer.

One parent reported:

My GP looked at her and said 'it's her leg' and even suggested we put something in her shoe, which was pointless. (Interview 4)

The GP said it was wing scapula but it obviously wasn't. . . . He didn't send her for any x-rays, he just looked at it and said she would be fine. (Interview 1)

Wing scapular was reported as the initial diagnosis in a number of cases and according to parents resulted in long time lapses to a scoliosis diagnosis. In some cases, this meant that surgery was the only option available leaving parents frustrated and angry. Some parents indicated that some GPs lacked knowledge of the condition and failed to refer for the x-rays needed that would confirm AIS.

Information Needs at point of diagnosis

Both literature and government policy reiterate the need for good information for patients. However, indications from this study are that there continues to be a lack of information available. All respondents reported a lack of written information. The majority of information was given verbally by the consultant at the point of diagnosis. In most cases the verbal information was not supplemented with written information.

However, Treweek *et al.* (2002) recognised that people forget half of what they are told within five minutes of leaving the consultation room. This view, supported by Van Schaik *et al.* (2007), was reiterated within this study.

While the consensus was clear that the information provided by the consultant was of good quality and accurate, the issue of information overload during the consultation was a problem and they often did not have enough time to formulate questions until much later. As a result there was a need for parents particularly to explore other sources of information in order to answer their questions. To this end Pellise and Sell (2009) highlighted the need for patients to have access to written materials that could be used as a tool in discussions with health professionals.

The timing of providing information would appear crucial for parents and young people. As awareness of the condition is generally low, basic information is often required prior to actual diagnosis by the consultant. Those young people presenting to GPs with pain or other physical abnormalities reported a lack of information from the GPs and that such information would have been useful on preparation for x-rays and consultation with the specialist.

Interview participants confirmed that their major source of information was the consultant at time of diagnosis. Many felt unprepared for the diagnosis and had insufficient prior knowledge on which to base questions at that time.

While all participants felt it would be useful to have general information about scoliosis, its causes, whether it is hereditary, and treatments, it was also identified

that the stage of diagnosis and ultimately the course of treatment for each individual scoliosis patient highlighted a difference in information needs between patients at the time of diagnosis. After some time to think about information needs, those people diagnosed with mild or moderate scoliosis wanted information regarding the progression of the condition, potential treatments (all those available) and limitations. Whereas those people diagnosed with more severe scoliosis and in need of surgery reported that more information was needed in terms of the surgery itself, the recovery time, length of hospital stay and scarring.

There were some differences in information needs between parents and young people as can be seen in Table 1.

Table 1: Differing information needs of the parent and child

Parent	Child
Why us? What could have been done to prevent it?	Coming to terms with the condition – what I need to do
How to identify scoliosis	Treatments – options (not only on surgery)
Effects of further growth on condition	Different Braces available
Symptoms	What braces can achieve
Effects on physical activity (before and after surgery)	Effects on physical activity (before and after surgery and longer term)
Treatments	The surgery procedures
Longer term impacts	Length of hospital stay – different scenarios, wards, care needed
Risks of surgery	After effects of surgery
Encouragement to make the right decisions	Impacts on school work
Pre-assessments for surgery	Talking to friends about the condition
Post-operative needs	

Some parents highlighted that they were asked to make a decision on treatment without a full understanding of the options and the positives of one treatment over another and also the negative outcomes of refusing a particular mode of treatment in terms of effects on the patient. One parent felt particularly pressured in having to make such a decision and felt it was particularly important that both the young person and the parents fully understood the reasoning behind the treatment proposed.

Some concerns were also raised as to how or if AIS is linked to other illnesses as some parents reported their children having heart problems, bunions, and respiratory

problems. There was a view that very little information was available to them that explored or explained related illnesses.

Availability of information

Overall the scope of information available to parents and young people is reported as limited, with the majority of information being received verbally. As previously mentioned the main source of information is the consultant at the hospital. The quality and accuracy of this information is not questioned albeit there was a general view that if given in isolation from other material it was not sufficient to meet the information needs of this group.

According to respondents, there is very little written information available either prior to or post diagnosis and this was identified as a major gap in provision. GP surgeries generally offer leaflets on a wide range of conditions but scoliosis is not included and parents identified this as a gap. A small number of the more recently diagnosed patients reported receiving a small amount of written information from the Scoliosis Specialist Nurse at the Trust. Those in receipt of such information reported that this information was of good quality and went some way to meeting their information needs. This information has only just been developed and is currently at a draft stage and being piloted.

There is some debate as to whether having access to full information would actually make it easier to come to terms with and deal with the impact of the diagnosis. Some parents report it would help them better prepare, others argue it would not

make any real difference as sometimes the more you know, the harder it is to understand and address it.

Parents and young people reported the need for information prior to first diagnosis. One parent stated:

They should tell you what it's all about instead of making you wait maybe 4 to 6 weeks to come and see a specialist who will tell you. They don't give you any paperwork or leaflets and maybe they should do something to put your mind at rest. (Interview 9)

Parents also reported the need for written information on the various stages of the condition and potential treatments. While it is accepted that some of this is covered in the meeting with the consultant, the consensus was that this was not enough for them to make informed decisions.

Most respondents reported that the quality of information they had received from the hospital was “satisfactory” with “room for improvement”.

Many parents reported feelings of shock at the diagnosis and this in itself hindered them taking in all the information provided at that time. They reported little opportunity to discuss the issues further with the consultant before their next appointments. Access to information during this period is currently being addressed for some by the involvement of the specialist nurse who can be contacted at any time for support and/or information.

The young people involved in the study felt that there was a need for specific information booklets aimed at the young people themselves. Such information should contain general and more specific information and that it would be useful to actually produce different booklets/leaflets for different stages and treatments of idiopathic scoliosis. There was a view that some information (verbal and on the Internet) was not provided in a youth friendly manner and that language should be adapted to suit this particular audience and that medical jargon should be avoided. The use of visual images was also seen as a way of improving understanding of the condition although it was recognised that there was a need to ensure these were not too graphic as this could create panic.

In the main, parents agreed that specific information should be available for their children but also that information answering the questions of parents should also be made available. It was also the view of some parents that even verbal information should be made more understandable.

Parent comments included:

I was ok with the information received . . . the only thing that baffled me was the names of scoliosis itself and we didn't get chance to ask . . . it was all Latin words and doctor words and we had to ask what is it a couple of times. It's a lot to take in and such big words obviously because the doctors talk in doctor terms that we are not used to. (Interview 9)

There were certain words he used that I didn't understand but I nodded anyway. (Interview 10)

Parent respondents reported their need to explore other information available. This was primarily limited to the time of first presenting to the GP through to the period immediately following the diagnosis by the consultant. The lack of information available from GPs often resulted in parents searching the Internet. The majority of parents involved in this study reported using the Internet as a way of accessing information about scoliosis.

They held the view that there was a lot of information about scoliosis available on the Internet. However, much of this is from outside of the UK and quite often not from accredited sites. The consultant did recommend that parents access the Scoliosis Association UK (SAUK) Website which most did. However, generally they used a search engine to find information and this allowed them access to a wide range of information, some of which ranged from helpful, not very helpful or too graphic.

A range of views were highlighted:

I went on some American sites and wished I hadn't because they are not very reassuring. (Interview 10)

I got the impression that it is routine, they make it sound very routine, very normal . . . I did actually feel better reading them after the first appointment. He did [the consultant] warn us just to use the accredited sites. (Interview 6)

I didn't find it useful, it's really scary because people put their own experiences on but out of context it's hard to know if she [her daughter] is going to be like that or not. (Interview 5)

Generally parents who had accessed information felt that information was widely available on the Internet and while the basic information on scoliosis was generally good, some was not relevant to UK practice and videos of operations were often frightening.

On the other hand some parents reported that some of the sites provided some positive aspects of information that they found very useful. This was particularly in terms of implications for their future lives. Furthermore being able to see someone who had had the operation and their recovery details was very useful and helped answer a lot of their questions. For some parents it helped make the link between the verbal information provided by the consultant and the reality of the given situation.

However, some concerns were raised about the accuracy of some of the information available on the Internet and its relevance to the UK. While most parents had accessed the recommended (SAUK) Website, it is notable that much of the information accessed through the Internet and discussed in the interviews originated in America and was seemingly more memorable primarily due to their use of visual images and videos. However, variations in treatments available in other countries caused some confusion for parents.

The SAUK Website received some positive reviews from parents. Generally there was a view that the information was good quality and user friendly. The fact that part of the Website was aimed directly at teenagers was regarded as most helpful.

Evidence from the interviews indicated that almost half of the young people involved, actively made a decision not to search for additional information on the Internet. This split does not appear to be age related or dependent on the curve magnitude of AIS or type of treatment. Some did not feel the need for or feel ready to absorb any more information, others left it to their parents to find and then pass on.

The natural curiosity of teenagers seems to be one reason for those actively seeking information in their own right and the Internet is an accepted medium for this group. However, some young people reported being upset and/or confused at the graphic nature of some of the information available, particularly that information related to surgical procedures. However, those that did access the Internet for information felt that many of their questions were answered and that the information was easily accessible to them. Those Websites aimed directly at teenagers were reported as most useful in providing information at the right level for that audience. One respondent registered on a Website that provided an opportunity to put their own questions to a health professional and receive responses. This was a model of information sharing that young people felt would be very useful to them.

For many respondents the Internet was the main source for written information available to them. Most used it to supplement verbal information provided by the consultant, others to better inform themselves prior to meeting the consultant. There is no evidence to suggest that any of the young people involved accessed information on the Internet prior to full diagnosis although some did follow up investigations to gain a better understanding of what they had been told.

Patient-Doctor interaction

Shaw & Wilson (2009) highlighted the importance of exchanging information and good communication enhancing a patient's perception of high quality care. As the majority of information available to respondents is provided verbally by the consultant, it is essential that both the young people and their parents receive good quality information and are provided the time to take on board the information provided and are able to ask questions.

Respondents reported positive relationships with the consultant involved in their diagnosis. They felt the information received was of good quality although as previously mentioned could have been offered in more user friendly language. The involvement of the specialist nurse appears to have increased the potential for information sharing and very positive relationships are becoming established and that access to information is improving.

Ideas for Improvement

It was agreed that a vast amount of information was available to both patients and carers through a range of sources. In the main, information on the Internet was easily accessible to both parties. There was also no dispute that the information provided by consultants and by SAUK is of good quality and goes some way to meeting the information needs of young people and their parents.

However, parents reported a view that the general awareness of scoliosis was low and some parents commented on the need to raise awareness of the condition, particularly its relevance to teenagers and how to spot curvatures.

Some questions were raised by respondents as to the model of information sharing currently available. Positive and negative aspects were identified in both verbal and Internet information by both patients and their parents as described earlier.

A key area for improvement was in the provision of information following GP referral. Parents felt this would be particularly beneficial in reducing stress levels, in preparing them for full diagnosis by the consultant and also providing them with some knowledge on which to base questions to the consultant. There was a view that leaflets and posters should be made available and should include:

- General information on scoliosis
- Simple ways for detecting scoliosis at home
- Basic information on stages and treatments
- What to expect on first hospital visit eg x-rays, scans etc.

Parents also held a view that verbal information provided on diagnosis should be supplemented with written information that can be taken away and looked at later. Ideally two sets of information should be designed one for the young person and one for their parents. Although similar in content, the language used should suit its specific audience. Young people pointed out their preference for more visual imagery, less text and no medical jargon.

Although some of the information highlighted to improve information sharing is already being provided, there was a view that an information pack that could be used for reference purposes would be most beneficial. Although no particular format was

favoured by respondents, parents generally felt that more in depth written information was necessary. Suggested content for parents included:

- Scoliosis Information – role of family history, side effects, known links
- Different stages of scoliosis
- Treatments for each stage
- Information on progression
- Surgery

Young people's information needs varied slightly as they felt a need for more practical advice. They suggested:

- General basic information – why it occurs, practical advice, side effects, key words and meanings
- Symptoms
- Living with AIS – ups and downs, what to expect
- Curvatures at different stages
- Physiotherapy – pros and cons and where to access it
- Braces – what will they achieve, different types, impact on mobility and activity
- Surgery – procedure, risks, recover time, hospital stay, scarring, post-operative physiotherapy and exercise needs
- Social and psychological effects of treatments
- Impacts on lifestyle – pre and post-surgery, sports, physical activities
- Telling your friends
- How to get in touch with other children/adolescents with scoliosis

Some young people felt that it was difficult to discuss scoliosis with their friends, particularly in the early stages. However, there was a view that this was needed and ultimately provided some good support networks.

In addition to the above, young people also identified a wish to be able to talk to other young people with the same condition about their experiences and learn from others on dealing with scoliosis. A blog or the use of social networking sites would be one way of facilitating this and is a favoured option of communication for young people generally.

National Perspective: Patient Survey Analysis

Background

In addition to the local perspective it was also important to gauge the national perspective in order to balance some of the possible local biases. In order to collect data from a national perspective a survey was designed based on the interview schedule used for the semi-structured interviews and also using observations made during the interview process. The questionnaire was piloted and findings informed the final version of the survey. This survey was then attached to the SAUK Website in order that patients visiting the site could chose to complete it (Appendix 2).

Demographic background

The data from a total of 22 responses were entered into the Statistical Package for the Social Sciences (SPSS) version 18 for analysis, responses to open ended questions were analysed separately. Respondents were asked to supply the first letters of their postcode to give an indication of the variation in regional response; responses indicated 18 different postcode areas. The mean age of the person with scoliosis at the time of diagnosis was 12 years of age (range 9-15). In 17 of the 22 cases the person with scoliosis completed the survey with their parents whilst five chose to complete the questionnaire alone. The ratio of girls/boys who responded to the survey was 4.5/1 with 18 of the respondents being female and 4 being male. This ratio is similar to the figure reported by Roach (1999) of male/female patients presenting with AIS.

The person most frequently responsible for identifying that there may be a problem was a parent or carer (59.1%) as can be seen in figure 1; this is in keeping with similar findings of Fazal & Edgar (2006). Other persons identified were; other family members such as brother and grandparent; a teacher; the person with scoliosis themselves and health professionals including general practitioners and a physiotherapist.

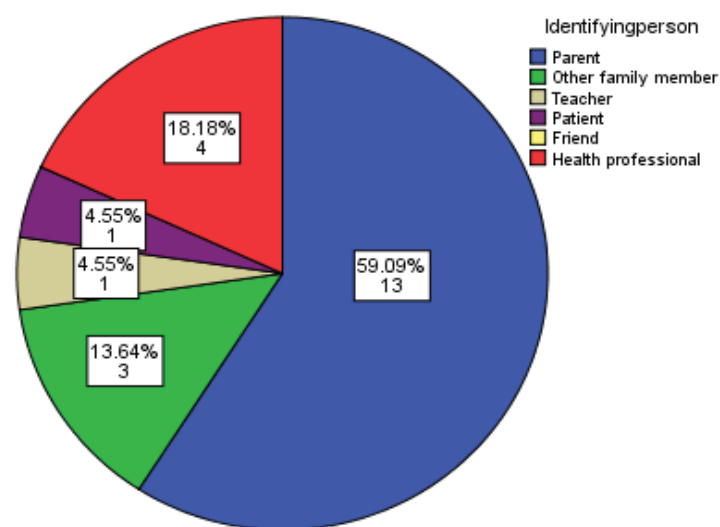


Figure 1: Who first identified that there may be a problem?

A variety of curve types were found among the respondents as is shown in figure 2. The most common curve reported was thoracic (10), similar numbers of respondents reported having thoracolumbar, lumbar and double-major curves. Although for the purposes of this survey the curve type was not sub-divided into a left or right handed curve. The distribution of curve type is representative of that reported in the literature with right-thoracic being the most frequently reported (Gore *et al.* 1981).

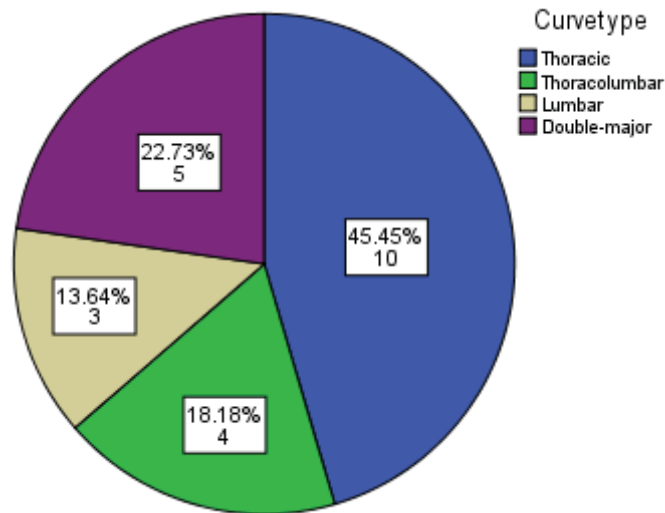


Figure 2: Distribution of respondents by curve type

The size of the curve at the first point of referral is reflected in the results in figure 3. It is pertinent to note that in over 80% of cases the curve was in excess of 30 degrees. This would mean that a significant number of patients are beyond the normal threshold for the prescription of conservative management techniques. By the same token Fazal & Edgar (2006) found, in a study of 100 consecutive AIS patients, that 56% of patients first presented with a curve greater than 40 degrees Cobb. It is commonly reported in a number of other health conditions that early diagnosis and treatment can lead to the most favourable outcome. It may therefore be suggested that a technique such as school screening or increased public awareness of scoliosis to promote earlier diagnosis and treatment may be beneficial in the field of scoliosis.

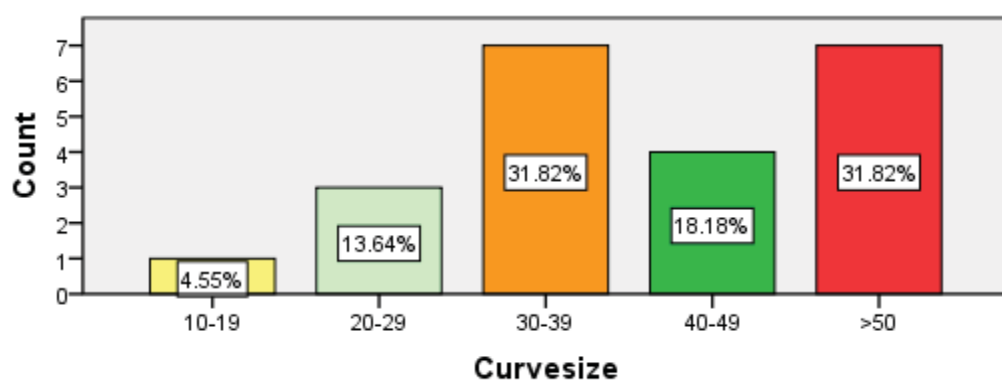


Figure 3: Distribution of respondents by curve size

Respondents to the survey were asked to indicate their feelings on being diagnosed/their child being diagnosed with scoliosis. A selection of responses, identified during observations made during the semi-structured interviews, was suggested and respondents were asked to select all that applied to them. In addition an alternative selection (other) was provided; this option was accompanied by an open text box into which respondents could suggest additional feelings. Figure 4 shows the number of times each response was selected. The most commonly experienced feelings were those of worry (13) and of being upset (12); the next most frequent responses were feelings of anxiousness (9) and nervousness (8). Responses identified through the 'other' option were of feeling strange, shock and disbelief and of feeling alone. One respondent reported 'feeling like a monster, a deformed young girl, a hunch back'. Two positive responses were also reported, one respondent described themselves as feeling 'okay' on being told they had scoliosis and another reported feeling 'reassured' that a cause had been identified for a hip imbalance.

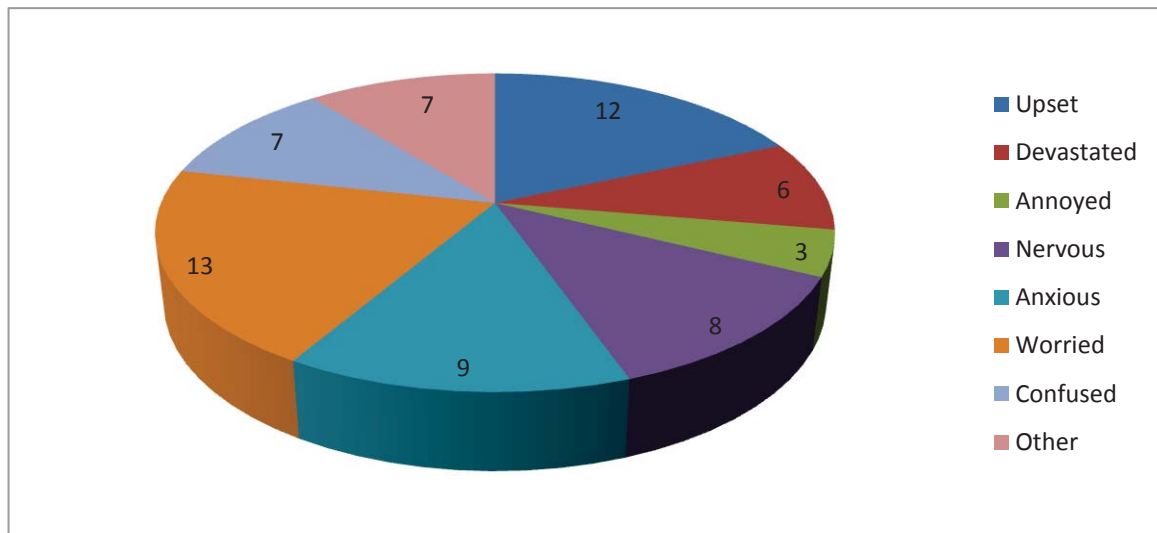


Figure 4: Feelings on being diagnosed with scoliosis.

The respondents were asked to indicate what questions they would most like to be answered in relation to their/their child's condition. Eight responses, which mostly related to the aetiology of the condition, were identified from observations made during the process of the semi-structured interviews. Respondents were asked to indicate all those which applied to them, an alternative option 'other' was also provided together with an open text box in which they could indicate alternate questions they would like answered. Figure 5 shows the number of times that each response was selected. Only one question, 'is it hereditary', previously identified from the semi-structured interviews was selected by less than half of the respondents. The other pre-suggested options were selected by almost three-quarters of the respondents which would indicate that the questions identified during the semi-structured interviews are those most important to people with scoliosis. A limited number of alternate questions (3) were suggested, implying that the questions identified during the semi-structured interviews are those that are relevant to most people with scoliosis. A limited number (3) of 'other' responses were

reported these questions asked, 'will the curve get worse/will it progress', 'is the curve obvious to see' and 'is there any connection to autism'.

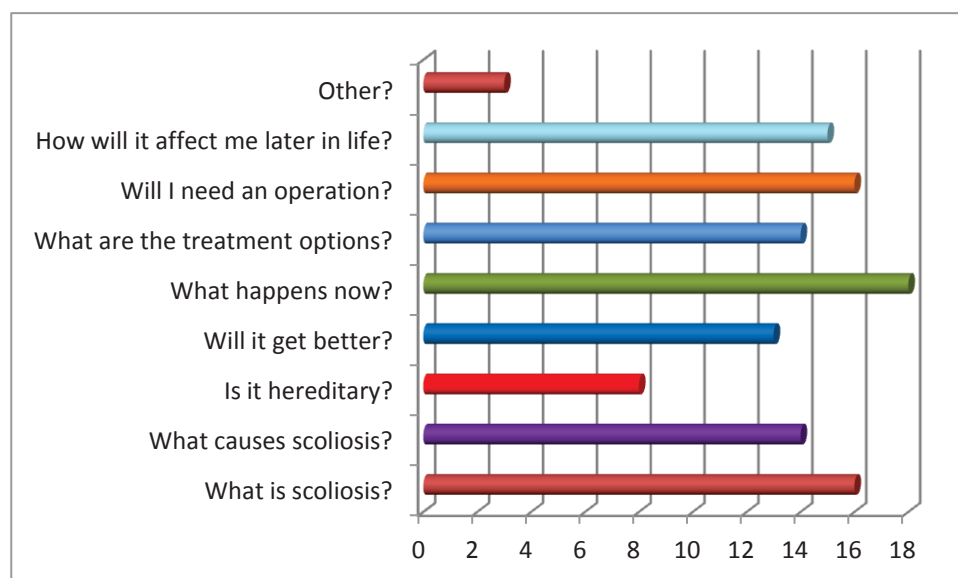


Figure 5: What questions would you like answering?

Respondents were asked to indicate whether they had received information regarding their condition. In 15 of the 22 cases respondents had received some sort of information relating to their condition. Those who indicated they had received information were asked which format the information had been in, verbal, written or electronic. Unfortunately none of the respondents provided an answer to this question. If respondents had not received any information they were asked to specify whether they would have preferred to be given information about their condition; all cases (7) agreed they would prefer to have been given some information material. A study by Vaidyanathan (2001) correspondingly found that 90% of participants within their study felt that written information about their condition would be beneficial. Those respondents who had received information were asked

to rate the information they were given on a scale of, very satisfactory, satisfactory, neither satisfactory or unsatisfactory, unsatisfactory, very unsatisfactory. The results of how respondents rated the information they received are displayed in figure 6.

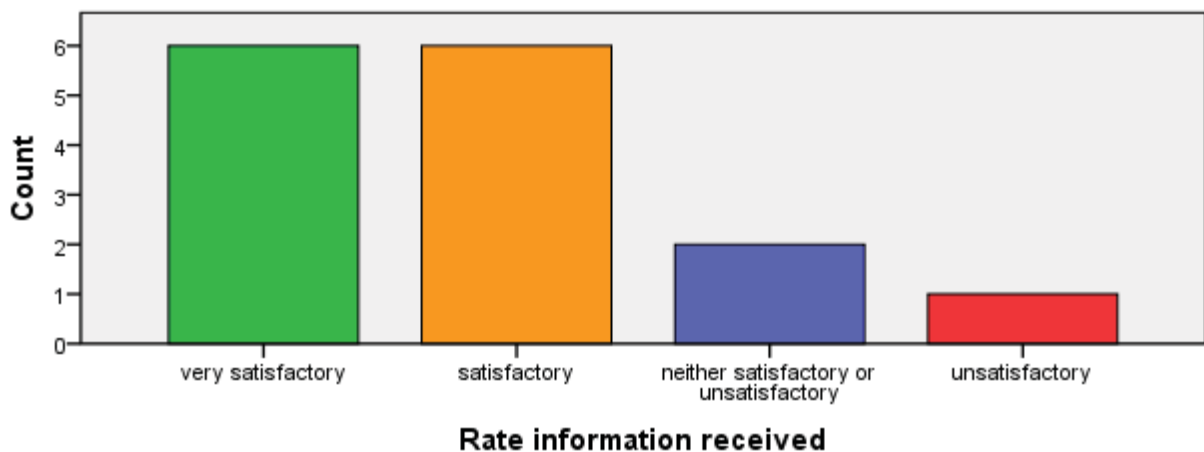


Figure 6: How would you rate the information you received?

Respondents were then asked to explain why they had chosen to rate the information they received this way. Generally respondents regarded the information they had received as useful and informative with 80% of them rating the information they received as satisfactory or better. Positive comments made by the respondents included praising the consultant for their knowledge and showing a careful approach to answering queries. Some of the respondents reported having been referred to a number of Websites, although they did not elaborate on the actual names of those Websites to which they were referred. In some cases the respondents had been referred to the SAUK Website, it could be assumed that this may be one of the aforementioned websites to which they had been referred, which they regarded as providing informative, useful, detailed information. The availability of a helpline through SAUK was found by some respondents to be extremely helpful. Those

respondents who indicated that they were not satisfied with the information they received described it as brief, basic, not much detail and 'got more information from the Internet'. These results and comments suggest variability in the quality of information and materials provided by different centres.

Suggestions as to how to improve the way information is delivered to people with scoliosis and their families was sought from respondents. A number of cases highlighted the importance of making the information child friendly. They also recognised the importance of explaining the condition to the child (patient) as well as to the parent/carer. One respondent suggested more information should be available from the GP, as there are leaflets available on a variety of health conditions but there is nothing for scoliosis. Respondents also recommended that the information be provided in written form to enable reference later, as one commented 'more written info to take away as you forget the stuff the doctor tells you in the clinic as it's all overwhelming'. In keeping with the suggestion of Coulter *et al.* (1999) that consultation times are limited. Two of the respondents mentioned that consultation time was also a problem in receiving the necessary information. In one case the respondent suggested a separate appointment to explain more fully the condition and to ask questions, whereas the other suggested the opportunity to come back and ask questions. Another person proposed that information should include a description of what scoliosis is, where help can be found to find out, more about the condition and also about the operation if they need one. This last point may imply that information provided needs to be specific to each individual's case and should reflect the stage of progression that they have reached.

Internet Access

Of the 22 respondents that completed the survey, 17 had accessed the Internet to look for further information regarding their condition. It was not indicated whether they accessed the Internet after they had been referred to it by the consultant or whether they had used their own initiative. Some reported that they could not remember which Websites they had accessed having visited a large number of sites, whilst others reported having used a search engine to locate relevant sites. The most frequently noted Website was that of SAUK, however whether this was due to the consultants referring them to this Website or whether they happened to find it through a search engine is unknown. Comments made by respondents about the Sauk Website were that it was generally useful, they liked the availability of a forum (although it was suggested that this could be improved through free access), it was more user friendly than other Websites and that they found being able to read others' experiences very useful. Where other Website names were identified they included, Scoliosis Nutty and the NHS Website, respondents also specified having visited a number of American Websites.

Comments on the standard of information found on the Internet varied widely from reassuring to scary and from very good and informative to confusing. One person reported the findings on the Internet as, 'often confusing and conflicting, especially as regards best treatment procedure and causes'. This suggestion of conflicting advice was supported by another respondent who reported finding conflicting advice surrounding different brace treatments. It could be implied that this is one of the dangers of searching for information on the Internet as quite often the information is

unregulated in regards of quality and validity. Some described the use of medical terminology on the Websites they had visited as confusing.

Support

Respondents to the survey were asked if a specialist nurse was present during the consultation and if so, was this helpful. In seven of the 14 cases there was a specialist nurse present and in five of these cases respondents agreed that they found this beneficial. This supports the opinions of the interview participants who also found the provision and involvement of a specialist nurse to be beneficial. Where explanations were given as to why they found this beneficial it was pointed out that the specialist nurse had been able to provide further explanation of the information given by the consultant. In one case the nurse had provided the patient/parent with a telephone number to contact them should they have any further questions after the consultation.

Respondents to the patient surveys were also asked if they had sought emotional support and furthermore did they think that emotional support should be made available. Eight of the 14 respondents said that they did not seek emotional support however half of these indicated that they had received emotional support from a family member. This could then imply that they interpreted the question to mean professional emotional support. One hundred per cent of the respondents believed that support, such as communication with others with same condition should be available.

Other Recommendations

Finally respondents were asked to provide any recommendations that they considered would be helpful in the production of, or dissemination of, information materials. There were a number of differing suggestions made, in one case it was recommended that some sort of awareness leaflet could be distributed to schools as their daughter had suffered bullying due to her condition. Publications that are easy to read, informative and provide links for specific advice on a variety of issues relating to scoliosis should be distributed throughout hospitals/specialist centres. It was mentioned that more information on holistic therapies should be made available for those with curves that are just beginning as much of the current information deals only with surgery. A number of respondents recommended the inclusion of success stories of others who have gone through the treatment process to offer reassurance. The inclusion of helpful Websites and telephone numbers of helplines was also thought to be important. It was recommended that there could perhaps be different information materials for different stages of progression of the condition, such as specific up to date information regarding bracing for those at that stage of their treatment. One respondent pointed out that it would be useful to know how to recognise/identify the condition in the first instance.

Conclusion

Both parents and young people identified a need for additional information and that verbal information as a standalone model is not sufficient. The evidence also clearly supports the need for access to information in the period between GP referral and visit to the consultant. There is also a view that general posters and leaflets on scoliosis should be available at GP surgeries as with other conditions as a way of

raising general awareness of the condition. Furthermore it was suggested that awareness of the condition should be improved within school environments due to the positive and negative implications mentioned on peer relationships.

Although no major concerns were raised on the quality of the verbal information provided, the language used could be improved. The use of medical terminology is reported as confusing for many and serves to reduce understanding; this was evident in all mediums by which information was accessed. Respondents requested that more user friendly language be used in verbal information sharing practices.

Information from Websites was generally regarded as useful and easy to access with the SAUK Website being particularly praised. However issues were raised about the graphic nature of some Websites that have resulted in causing stress and in some cases panic. Concerns were also raised as to the credibility of some Websites and their relevance to UK practice which could result in further confusion. The Websites recommended by consultants received positive feedback, although there was a view that these could be improved. However quite often parents related a tendency to look beyond these when seeking information and therefore a list of recommended credible Websites would be beneficial for seeking additional information.

Information needs of parents do appear to vary from those of young people, as does the way in which it should be presented. Young people show preferences for less text, the use of simple language and more visual imagery. In terms of information needs, parents generally opted for easily understandable, factual information about the condition, how it may progress and the treatment options available. Alternately

the young people stated preferences for information about the more practical aspects of the condition and its implications on their lifestyle. Although they also felt a need for improved information on potential treatments and surgery, this again focused on the more practical issues of treatments. Examples of this are, how comfortable is it to wear a brace, would a brace limit mobility, how long would they be in hospital following surgery, how big would the scar be and what would it look like?

In conclusion, there continues to be a need to improve the availability of information on scoliosis, particularly in written form and to provide more information about relevant Websites for those choosing to seek additional information. There is a need for all information to be user friendly and in a language that is easily understandable. Separate information packs using different formats for parents and young people are felt to be more beneficial in addressing the information needs of both groups. Young people also felt that some guidance in how to talk about their condition and what it means to their friends was important as many did not know how to or feel ready to do this. The opportunity to communicate with others suffering from AIS, listen to their experiences and to learn from each other was felt to be an important step forward in meeting the information needs of young people.

A survey of UK NHS scoliosis consultants.

Background: Service users' health information needs are very frequently not completely addressed in hospital clinics. The role of the patient as an active partner in health care is now widely accepted and providing information to patients is considered fundamental.

Purpose: The purpose of this survey was to determine what information is currently provided by consultants at NHS scoliosis centres in the UK at the point of first diagnosis of patients with AIS.

Survey participants:

Participants were senior scoliosis consultants working in, or in partnership with, the major UK scoliosis centres.

Methods:

Instrumentation:

An electronic survey was emailed to senior consultants at 30 key scoliosis centres in the UK. The survey covered questions relating to the most common questions asked by service users when first diagnosed, whether any written information was provided and who had written this and whether patients were referred to any relevant Websites. The specific questions included in the survey can be seen in a copy of the survey (Appendix 3).

Procedure

A senior scoliosis consultant was identified from each of the 30 main scoliosis centres in the UK. The 30 centres were selected purposively to cover a range of geographical areas and centre sizes, where necessary with the help of the British Scoliosis Research Foundation (BSRF). The consultants were identified from a list held by the BSRF of all the scoliosis centres and consultants. The consultants were then contacted by email, given full information about the survey and invited to take part.

Results

A response rate of 47% was achieved (n=14). Questions 1 and 2 related to the most common questions asked by service users and their parents. These were identified as, aetiology (22.5%), prognosis (42.6%), general treatment (16.8%), surgery (12.4%) and parental guilt (5.6%) (Figure 7).

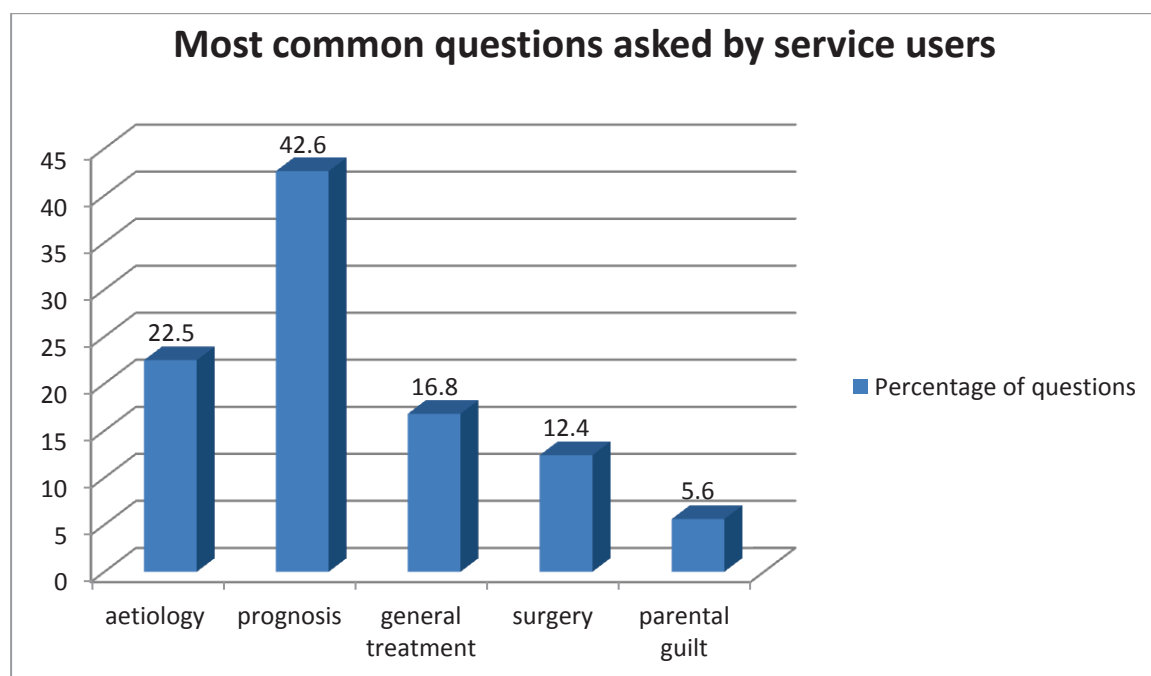


Figure 7: Most common questions asked by service users

Question 3 which asked whether the adolescents with idiopathic scoliosis and/or their parents were given any written information found that 11 consultants (78.6%) answered yes and 3 (21.4%) answered no (Figure 8).

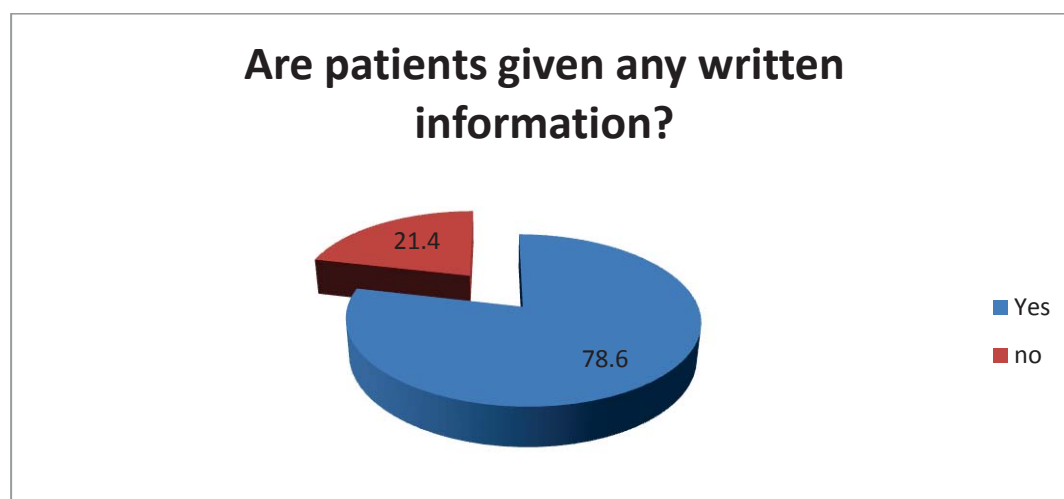


Figure 8: Are patients provided with any written information

Question 4 of the survey asked the consultant to identify the five most important topics that the information provided aimed to cover. Overall the topics included were: the causes or aetiology of scoliosis, the natural history, the clinical presentation, the types of management including benefits and risk factors, related Websites and special interest groups and who to contact for more information and how to contact other patients.

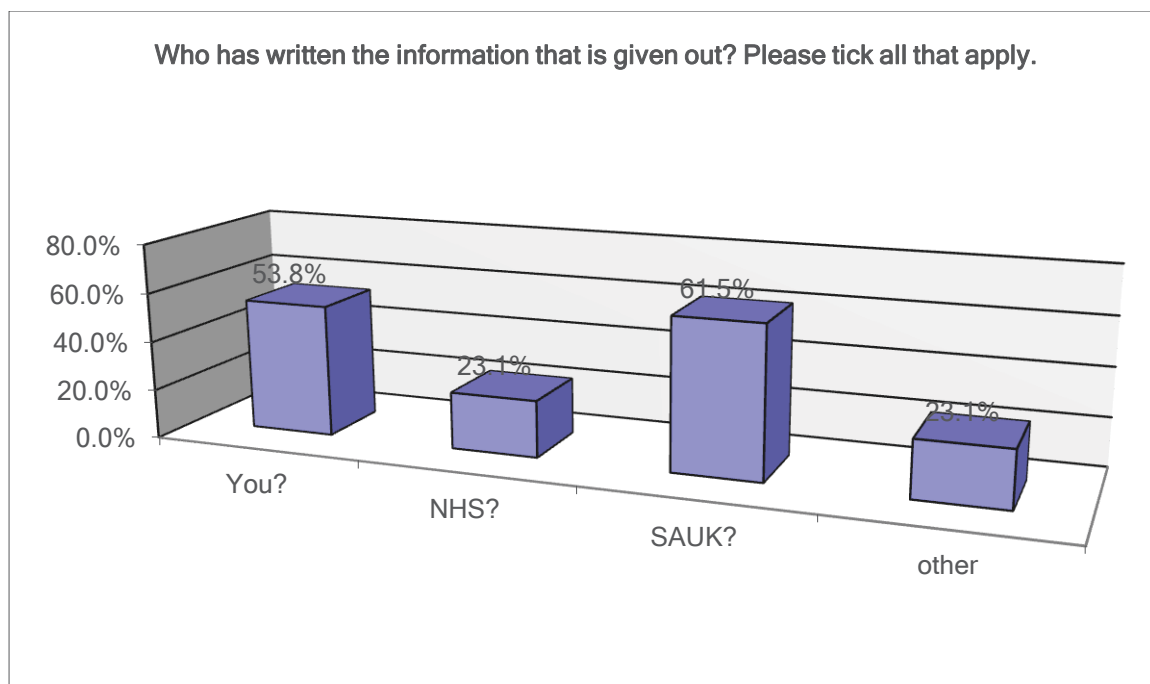


Figure 9: Who has written the information that is given out?

78.6% of consultants said that patients were provided with written information provided by themselves or a member of staff. This information was produced by the NHS in 23.1% of the cases, the Scoliosis Association UK in 61.5%, and 23.1% of the time by other sources (Figure 9).

When surgeons were asked how people with a diagnosis of adolescent idiopathic scoliosis and their parent/carers accessed the written information, the replies indicated that in 76.9 % of cases a member of staff gave them the written information, in 38.5% of cases written information was available in the hospital for them to pick up and in 38.5% of cases patients got them from other sources (Figure 10).

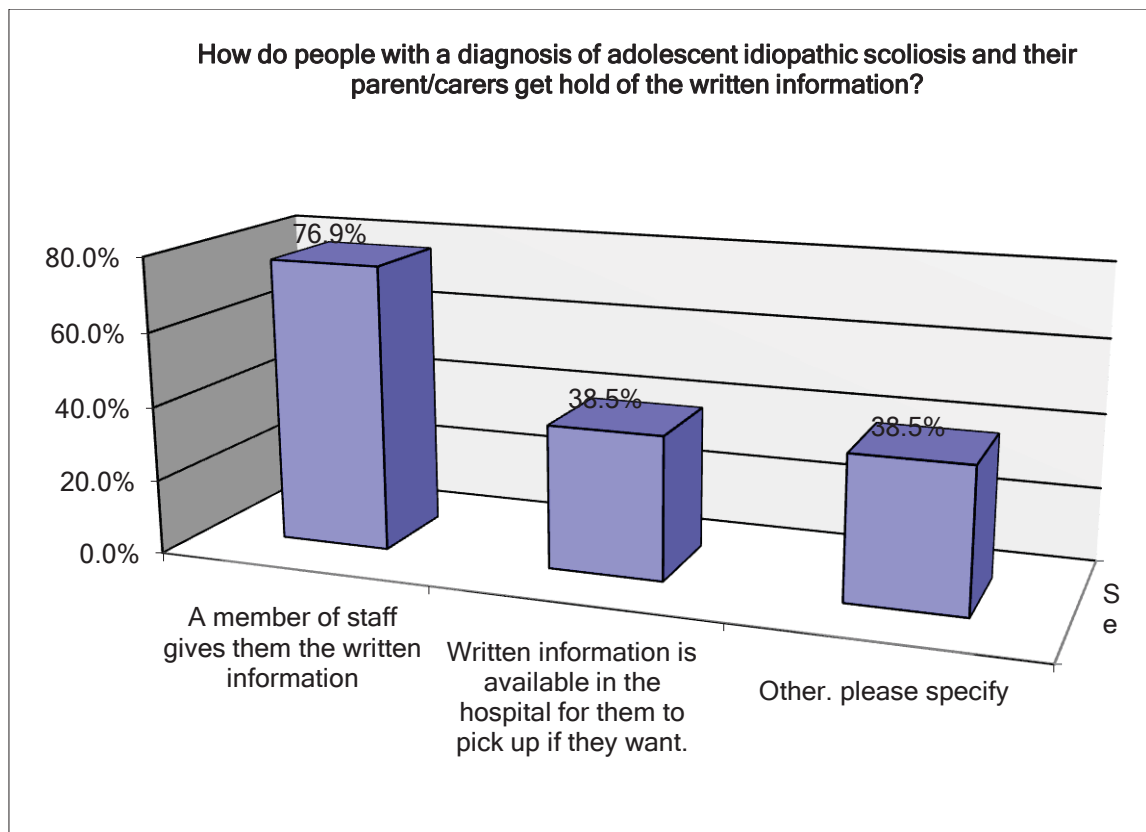


Figure 10: Ways which patients with AIS get hold of written information

Finally when surgeons were asked if there was anything else that they thought would be useful for us to know, surgeons stressed the importance for information to be evidence-based, address patients' anxieties and counselling needs, provide clear natural history information and address ways of contacting other patients with AIS who have or have not undergone surgery.

Discussion

AIS patients at the point of first diagnosis at hospital are provided with relevant information or referred to relevant Websites in a significant number of scoliosis UK centres. However it is important to remember that these results represent the views of less than half of the scoliosis consultants contacted. Whether or not the other 50%

of consultants who did respond provide any written information to patients is not known.

According to senior scoliosis consultants, the most common questions asked by service users related to the causes, prognosis, general treatment (especially surgery) and parental guilt. Most surgeons also reported that patients were provided with written information that aimed to cover the causes of scoliosis, the natural history, the clinical presentation, the types of management available for scoliosis patients (including the benefits and risk factors) scoliosis-related Websites and special interest groups as well as who to contact for more information and how contact to other patients. Apparently none of the information covered issues relating to parental guilt, counselling needs or the emotional aspects of living with scoliosis. The written information that was actually provided was written mainly by the surgeons themselves as well as SAUK with a smaller proportion of information provided by other sources.

Surgeons stressed the importance for information to be evidence-based, address patients' anxieties and counselling needs, provide clear natural history information and address ways of contacting other patients with AIS who have or have not undergone surgery. Initial results from this survey of Consultant surgeons' views suggest that whilst a large number of patients information needs are being addressed (causes, prognosis, management and risks and benefits), other aspects such as parental guilt, anxieties, counselling needs and other emotional needs are not however sufficiently addressed in the written information currently provided. This consultant survey also demonstrates that to some degree, the information that

Consultants suggest that patients want to know (consultant survey) is quite congruent with the information that the patients themselves have said they needed and wanted to know. This suggests that Consultants in the UK appear to have a good awareness of the information needs of service users. However this awareness does not appear to have been transferred to the presentation of the written information that is currently provided to patients.

Analysis of Websites suggested by Scoliosis consultants to adolescent idiopathic scoliosis patients attending specialist scoliosis centres in the UK.

Background

To support information provided during consultation, whether this is verbal written or both, health professionals commonly recommend other sources of information material. The use of electronic means to access health information is becoming increasingly more popular as the Internet becomes more widely available. One of the main problems with the large quantities of easily accessible information available on the Internet is that it is unregulated and so allows anyone to publish health-related information (Mathur *et al.* 2005). The issue then becomes finding information that is both valid and credible. To address concerns about quality, a plethora of tools and guidelines have been developed for producing and evaluating online information. However a study by Gagliardi and Jadad (2002) examined 98 instruments and found that none of these seemed to have been validated.

One instrument for analysing the validity and credence of written health information that has been validated is the DISCERN instrument (Charnock *et al.* 1999). This instrument was found to have good levels of both inter-rater reliability and validity and also involved consumers at every stage of development. As the instrument deals with the content of the written information it should therefore be applicable to online information.

Aim

The aim of this study was to examine, for quality and reliability, the information content of Websites that are suggested by clinicians to adolescent idiopathic scoliosis patients attending specialist scoliosis centres in the UK.

Methods

Instrumentation:

The DISCERN instrument was designed to enable patients and information providers to judge the quality of written information about treatment choices. The instrument consists of 16 questions, scored on a five point likert scale, that are divided into three sections. The first section consists of eight questions that examine the reliability of the publication the second section contains seven questions evaluating the quality of the information contained within the publication and the third section contains one question to give an overall rating of the publication. The DISCERN instrument website states that it aims to ensure that:

“Good quality written consumer health information about treatment choices will be accurate and will be based on the best and most up-to-date scientific evidence. It will help you consider all aspects of a treatment choice, including the outcomes of a treatment choice and any areas of uncertainty. It is possible that issues other than clinical effectiveness will also be important when deciding about treatment and good quality information will help you to choose the option that is best for you”

(http://www.discern.org.uk/background_to_discern.phpt):

Procedure

Clinicians from 14 specialist scoliosis centres responded to a survey that included a question regarding which Websites they recommend to AIS patients. Eight Websites were identified from the responses to this question. These were, Scoliosis Association UK (SAUK), British Scoliosis Society (BSS), Scoliosis Research Society (SRS), British Scoliosis Research Foundation (BSRF), British Association of Spinal Surgeons (BASS), Eurospine, Medikidz and iScoliosis. These Websites were independently analysed by three researchers for content and relevance using the DISCERN instrument. The reviewers' scores for items 1 to 15 were added together to give a summative score for each reviewer for each Website. The summative scores were then tested for correlation using the non-parametric test Kendall's Tau. The websites were then ranked (1 being the best, 7 being the worst) based on the total score achieved. Comparisons were then drawn between the ranking of the Website based on the summative score and the overall rating of the Website as given for item 16.

Results

The summative score given by each reviewer for items 1 to 15 of the DISCERN instrument for the Websites are shown in Table 2.

Researcher	SAUK	SRS	BSS	iScoliosis	BASS	Eurospine	Medikidz	BSRF
1	47	41	35	48	29	41	30	Unsuitable
2	40	37	36	50	23	45	24	Research
3	29	29	29	31	16	32	29	Based

Table 2 Total scores for each Website (Max=80, Min=16).

Significant correlations were found between the total scores for researchers 1&2 ($p = 0.006$, $\tau = 0.878$) and researchers 2&3 ($p = 0.029$, $\tau = 0.732$). A moderate correlation ($\tau = 0.577$) was found between researchers 1&3, however this failed to

reach significance ($p = 0.91$). The Website rankings based on the summative score given to each Website by each researcher are displayed in Table 3. The “scorers” included one Psychology Professor, one Physiotherapy Senior lecturer and one PhD student. The implications of these results are that the scores obtained from the Discern instrument may differ based on the person scoring it. Different people as well as different professional groups may have different interpretations and understanding of the questions asked.

Researcher	SAUK	SRS	BSS	iscoliosis	BASS	Eurospine	Medikidz	BSRF
1	2	4	5	1	7	3	6	Unsuitable
2	3	4	5	1	7	2	6	Research
3	3	3	3	2	7	1	3	Based

Table 3: Website ranking based on summative score (1=best, 7=worst)

Researcher	SAUK	SRS	BS	iscoliosis	BASS	Eurospine	Medikidz	BSRF
1	3	2	2	3	1	3	2	Unsuitable
2	4	3	2	3	1	3	1	Research
3	1	2	2	3	1	2	2	Based

Table 4: Score for the overall rating of the Website (5=highest, 1=lowest)

Discussion

None of the Websites evaluated in this study scored more than 50 (62.5%) on the DISCERN instrument. The implications of this are that the information provided on these Websites may not be very accurate and trustworthy and may not be meeting patient needs. A problem noted with all of the Websites evaluated was the failure to identify the source of the information contained on the Website and also the date it was produced. If the information is from a reliable, credible source then this should

be made apparent in order that this may increase users' confidence in what they are reading. It is also important to specify the date the information was produced so users' can be confident that they are reading up-to-date, relevant material. No one Website was particularly strong in any section although good scores were achieved on individual questions. Websites that scored poorly were particularly weak in section 2 of the instrument, specifically how treatments work and their associated risks and benefits. The Website that scored best in section 2 was iScoliosis, it is worth noting however that this is an American Website and the information may be reflective of differing treatment pathways to those in the UK. Information relating to the signs, symptoms and aetiology of the condition were generally well presented on all Websites evaluated; this is an area which has been highlighted as important to AIS patients and their families. The areas where the SAUK Website was particularly strong were in describing its aims and the relevance of the content. The SAUK Website was also strong in the provision of links to alternative sources of information and in support for shared decision making. Weak areas that could be improved were the lack of source identification and date, descriptions of how treatments work, the associated risks and benefits of treatments and how treatment choices can affect overall quality of life. This final point was an area of weakness noted in all Websites evaluated and yet quality of life is considered to be of great importance to AIS patients and their families. The results for the overall rating of the website in Table 4 provided an insight into the usefulness of the Website as a source of health-information related to the condition. The summative scores presented in Table 2 were more useful for drawing comparisons between sources of information and ranking them accordingly as in Table 3. Although it should be noted that the summative scores do not identify the areas in which a particular Website may be

either strong or weak. It may be suggested that adhering to the criteria for the questions on the DISCERN instrument could ensure the production of a useful, informative, reliable and credible Website.

Conclusions

If healthcare professionals are to suggest Websites to patients as a source of further information they should be aware of the content of those Websites to enable them to make the most appropriate recommendations. Websites designed to act as a source of health-related information should be maintained in such a way that the information contained is up to date, evidence based, impartial and written in plain language. Consideration should be given to the information needs of AIS patients and their families and also to what is important to these users in the design of the Website. In addition the Websites should be designed in such a way that the content should be tailored to suit the patients' information needs.

A content analysis of information provided to AIS patients and their parents from a cross-section of NHS scoliosis hospital clinics

Aim

The primary aim of this study was to evaluate the content of the hospital information material that is currently provided to AIS patients at the first point of diagnosis in hospital scoliosis clinics. The secondary aim was to evaluate whether this information was meeting service user's needs.

Methods

Content analysis (CA) is an established and widely used method of document analysis and can be used with quantitative or qualitative data and in a deductive or inductive way (Elo & Kyngäs, 2008). It has been defined as '...any technique for making inferences by objectively and systematically identifying specified characteristics of messages'.¹

In a CA, the texts to be analysed are typically systematically scanned for key words or concepts. These can then be quantified or thematically analysed. CA is a flexible analytic method and the particular approach used depends on the focus of the research, the nature and scope of the texts and also on existing knowledge about the subject area. Hsieh and Shannon (2005) observe that, rather than being a single method, there are at least three different CA methods: conventional, directed or summative. In the first, coding categories are derived directly from the text and are not formulated beforehand. With the directed approach, the analysis starts with a theory or existing research findings as guidance for initial codes. A summative

content analysis involves counting of, and comparisons between, key words or content (Holsti, 1969).

Given this flexibility in approaches to CA, the methods used here were 'conventional' (with a simple thematic analysis of the data) as well as 'summative' (though categories or key concepts were not counted but described in tabular and narrative form).

The texts analysed were documents obtained from nine sources. All these texts were focused on provision of information to patients with scoliosis.

Results

1. Summative (description of texts: narrative and tabular)

The first stage in the CA was to describe texts according to source (NHS Trust or other), the number of each text from each source and type of text (advice leaflet or other). See Table 5.

Source		Number of texts*	Type of texts**
1	The Royal Orthopaedic hospital, Birmingham	6	Guide for patients, information leaflet, questionnaire, pre-op assessment guides
2	Addenbroke's Hospital, Cambridge	4	Information sheets
3	Sheffield Children's NHS Foundation Trust	11	Information leaflets
4	Guy's and St Thomas' NHS Foundation (Evelina Children's Hospital)	2	Information leaflets
5	James Cook	1	Questions and Answers leaflet
6	North Bristol NHS Trust	4	Information leaflet
7	Cardiff and Vale NHS Trust	1	Advice booklet
8	Northern Ireland	1	Surgery guide (sourced from British Scoliosis Society website)
9	Salford Royal NHS Foundation Trust	1	Patient information
		N=31	

Table 5: Overview of texts

* It was not possible to ascertain the exact number of discrete texts because some texts were amalgamated with others so this is an approximate number. ** This is based on information provided by the author(s) of the text.

The main texts from each source were then read and described in relation to their main features (content, tone and presentation). Ancillary texts were also briefly read, though the main text was used primarily for analysis since main and ancillary texts were often very similar (in focus, content, etc). See Table 6.

Table 6: Description of texts

Source	Main text (s)	Main features	Ancillary texts
1. The Royal Orthopaedic hospital, Birmingham	A Guide for Patients	Content: defines scoliosis; what it means for patient; experience of pain; gender differences; diagnosis; treatment; quality of life issues; risks associated with treatment options; team; Websites and other links Tone: brief, to-the-point Presentation: small, white with black text	<ul style="list-style-type: none"> • Various (inc. Pre-operative assessment for patients requiring spinal cord monitoring; Information about scoliosis; questionnaire)
2. Addenbroke's Hospital, Cambridge	Information about Surgery for Scoliosis in under 16 year olds	Content: defines scoliosis; treatment; post-operative period; team; admission; links Tone: to-the-point Presentation: white with black text	<ul style="list-style-type: none"> • Various (inc. Information about Surgery)
3. Sheffield Children's NHS Foundation Trust	Scoliosis	Content: defines scoliosis; causes; signs; treatment Tone: brief, to-the-point Presentation: white with black text, coloured, image and text based	<ul style="list-style-type: none"> • Various (Use of analgesia; Blood Transfusion; Bracing; Discharge)
4. Guy's and St Thomas' NHS Foundation (Evelina Children's Hospital)	About Scoliosis	Content: describes spine; defines scoliosis; causes; symptoms; prevention; treatment; bracing; risks; surgery; admission; post-operative period; story about scoliosis patient (child and parent's perspectives); letter to school; parent's accommodation; facilities Tone: to-the-point Presentation: image and text-based, on yellow paper	<ul style="list-style-type: none"> • Idiopathic Scoliosis
5. James Cook	Scoliosis-Questions and	Content: defines scoliosis; causes; prevalence; diagnosis; treatment; quality of	

	Answers	life issues Tone: brief, to-the-point Presentation: white with black text, image and text based	
6. North Bristol	Preparing for Your Spinal Surgery	Content: preparation for surgery; medication; allergies; risks; post-operative period; going home Tone: brief, to-the-point Presentation: white with black text, image and text based	<ul style="list-style-type: none"> • Various (inc. Posterior Spinal Fusion; Lumbar Microsectomy; Posterior Lumbar Decompression)
7. Cardiff and Vale NHS Trust	Scoliosis in Children and Young Adults	Content: description of spine; definition of scoliosis; experience of having scoliosis; treatment; admission; experience of being on a ward; the operation; post-operative period; things to remember Tone: young person-friendly, accessible Presentation: colourful, image and text based	
8. Northern Ireland	Scoliosis: a Pre and Post Surgery Guide	Content: defines scoliosis; anatomy of the spine; pre-op tests; post-op tips; concerns; coming home; timescales; treatment; patients' stories; support Tone: friendly, accessible Presentation: mostly black text on white, image and text based	
9. Salford Royal NHS Foundation Trust	Spinal Fusion or Spinal Decompression	Content: definition of spinal fusion; surgery; spinal decompression; assessment; complications; recovery; surgery and after; mobility Tone: to-the-point Presentation: mostly black text on white, coloured front page, image and text based	

In terms of *type* of text, there was some variability in how these had been described by the author(s). Most texts were described as 'information' leaflets or guides. Importantly, it was not always clear for whom the texts had been written--some seemed to have been written for children and young people, while parents and carers were the intended audience for other texts. In one case (Birmingham), texts had been provided which were intended for medical practitioners.

In relation to the main *features* of the texts, there were some core features that were common to all texts. These were: definitions of scoliosis, symptoms, causes and treatment options. Many texts provided information about the risks associated with surgery, pre-admission routines and (to a lesser degree) the experience of living with scoliosis. Only two featured patient (child and child and parent) stories.

Author(s) appeared to have attempted to avoid overly technical language (with varying degrees of success), though most texts were (relatively) accessible in that to-the-point, factual language was used and in some cases the tone was friendly or even warm.

The texts varied little in terms of presentation. All were paper-based (though they may also be available electronically) and most were black text on white paper. Colourful front pages were available on texts from three sources and many used images (though of varying quality; some were of poor quality).

2. Thematic content analysis

After the descriptive (summative) CA, the texts were read again to derive main concepts and themes.

There are issues relating primarily to generalisability that should be flagged up at this point. We do not know if these documents are routinely given out to all patients or only given to some (maybe those that ask for information). Are these the only documents given to patients, or is other information (in another format) also provided to newly diagnosed patients? Are these the most up-to-date information texts available?

It is also important to note here that, given the limited scope of the texts (all were patient information leaflets dealing with a particular medical condition), this analysis is necessarily limited. The data were not rich enough to properly observe themes, and the themes described below might be more appropriately described as 'observations'. There are three made here:

- The dominance of provision of basic medical information

It is hardly surprising that medical information about the condition (scoliosis) dominates the texts given that all are described as information leaflets. This information encompassed description of the condition, its prevalence and its treatment. It may also have included advice on the process of admission to hospital and pre-operative requirements.

- The impact on quality of life of the condition is acknowledged, but is peripheral

Many texts made reference to living with pain, managing pain, anxiety about the condition or its treatment, but these were often 'side' issues and rarely properly addressed. It is quite striking that, given that some of these texts were aimed at adolescents, there was little discussion of adolescent-relevant issues (identity, image, sexuality). Two texts contained patient stories (with photographs) which helped bring quality of life issues to the fore.

- It is not clear for whom the text is intended and there is a general lack of attention to detail in the texts

Authors had attempted to avoid use of overly technical language and in some cases had employed accessible, even friendly, language. Images and colours had been used (most notably in the Welsh case, where cartoon imagery was also used). However, it was not always clear for whom the text was intended (children or their parents). Image quality was poor or images were not used when they might have been. Most were not very well laid out and many seemed 'ad hoc' and hastily created. This undermined the purpose of many texts.

Discussion

Around 31 texts from nine sources were subjected to a CA. These texts were categorised according to their type, content, tone and presentation and described in tabular and narrative form. Three main observations were then made about the texts: that they are focused primarily on provision of medical information; that quality of life issues are peripheral within them; and that they are sometimes confused about their intended audience (and, therefore, their purpose).

We do not know enough about what other information (in verbal form, written, electronic) is given to patients at the point of diagnosis. It is possible that the texts used here are provided to patients with other documents, maybe ones with a more psycho-social orientation where the impact of scoliosis on quality of life (and everyday activities) and patient fears around the condition are discussed in more detail. Patients may also be accessing the Internet for help and advice, and information garnered this way may be used to complement the information leaflets described here.

In many respects, the leaflets achieve their stated aim: they provide basic information to patients with scoliosis. The analysis here should be regarded as preliminary and would be much improved with a larger sample of (more diverse) texts from a wider range of sources.

Discussion

This study aimed to evaluate patients' information needs at the first point of diagnosis with AIS at hospital. The overall findings highlighted deficiencies in the timeliness, pertinence, content, format and quality of information for patients and their families at the point of diagnosis.

A key issue in the study was the difficulty in identifying exactly when the 'point of first diagnoses' occurred. This was because formal diagnosis could be delayed and could occur at any time after the patient and family had first approached the GP. This could be anything from the 18 week wait for a first hospital consultation currently recommended by the NHS, to several months delay due to GPs sending patients home on the first visit. Misdiagnosis was the main reason for many delays and such misdiagnosis reduced the treatment options for some patients in this study. This resulted in several patients having no opportunity to be treated conservatively and being obliged to have surgery. The implications are outside the scope of this study but suggest that GPs need better education in recognising and diagnosing AIS.

It was clear that for many patients there was not a clear 'point of diagnosis', instead they travelled along a diagnosis trajectory. The trajectory started when they suspected something might be wrong, it continued when they approached their GP and culminated in the consultation with the hospital doctor. At each stage of this trajectory, patients and their families had differing information needs. There is an argument that the trajectory should actually start at the age of 10 years old when children and their families need to be made aware of the condition and how to check for it.

Even when patients were accurately and quickly diagnosed by their GP, there was a lack of information available to patients and their families during the time they were waiting for their hospital referral. This was identified by participants in this study as an area for improvement. Patients and families wanted information about the condition after they had seen their GP but before their hospital appointment so they could be better prepared for the hospital consultation. This finding is similar to that in studies relating to information needs in other health conditions (Cassileth *et al.* 1980, Strull *et al.* 1984). The implications are that GP surgeries should accept responsibility for providing basic information on the condition to patients and their families and should also be able to suggest further appropriate sources of information.

The main source of information for many of the patients in this study was the hospital consultation. Participants acknowledged that in addition to verbal information currently provided they needed written information as well that they could take away to consider after the consultation. This finding is supported by Treweek *et al.* (2002), who highlighted that people forget half of what they are told within five minutes of leaving the consultation room and Van Schaik *et al.* (2007), who reported patients self-reported 'poor' knowledge about their condition. In contrast, patients who had been exposed to an amalgamation of written and verbal advice have been shown to have an increased capability to recall the information than those who were given verbal advice only (Gauld 1981). The implications of this are clear; it is vital that the patient leaves the consultation with a written summary of the information they has been given verbally. Patients' preferences were for this summary to be provided in two formats, one for the parents and another summary with more visual leaflets

written in age appropriate language for the children or teenagers. Written information provided should also be targeted to the patients' curve severity, age and specific stage of the progression of scoliosis. Providing patients with small curves and their parents information on surgery when their current treatment necessitates either observation or bracing is very likely to cause them unnecessary stress and anxiety. Furthermore, they should be signposted to other good quality sources of information that are appropriate to their needs.

A range of health information leaflets pertaining to scoliosis, currently being provided from a range of hospitals in the UK were identified in this study. A content analysis of these leaflets highlighted the major focus to be the medical aspects of the condition such as causes, prognosis, management and risks as well as benefits of treatments. Psycho-social, emotional and quality of life aspects were less well addressed. These findings were born out in the interviews with patients and their families. Participants also expressed a desire for information on issues such as caring for someone with scoliosis, quality of life issues, patient and family stories, and how to access counselling and other support services.

Very little information on aspects of identity, self-image and sexuality were included in the leaflets examined for this study. This was of particular concern as this condition affects adolescents who generally experience issues with self-esteem, self-confidence and identity. Many recent studies have (Button et al, 1993, Rosen et al, 1997, Silverstone, 1992) demonstrated that disruptions in the formation and stability of one's self-esteem can lead to various psychological problems such as eating disorders (anorexia and bulimia nervosa) in adolescents **without** AIS.

Neglecting to address these issues in patients with AIS could result in an even greater risk of these problems.

In a related research study Smith *et al.* (2002) found a relationship between a diagnosis of AIS and low body-weight which may indicate disordered eating and is thus a cause for concern, particularly in the light of the well-established relationship between eating psychopathology and osteoporosis. Aspects of organic health may need to be considered in addition to the cosmetic deformity.

Further in addition to leaflets, consultants recommend a number Websites to their patients. An analysis of the validity and credence of the eight Websites recommended by consultants highlighted the variable quality of the written health information presented. The best performing Website as judged by the DISCERN tool was iScoliosis. The particular strengths of this Website were that it scored well in section 2 of the DISCERN instrument which evaluated information relating to treatment choices, what choices are available, how they work, their risks and benefits and support for shared decision making. A caveat to this, is that this is an American Website and so may contain information that could be contradictory to the treatment pathways available in the UK. The BASS was the worst performing, in particular this Website did not provide any information that related to many of the criteria evaluated by the DISCERN instrument and seemed to be a Website designed for surgeons only.

A number of web-sites such as the BSS and the BASS sites that are currently recommended by consultants to service users provide information that is mainly for

health care professionals. Information that is directly relevant for patients and their carers is very limited. Even though some disparities were noted, the findings in this chapter are still highly relevant and give a clear indication that healthcare professionals would be wise to check the content of websites before recommending them.

The SAUK website was found to be strong in the statement and achievement of its aims and the relevance of the information contained on the Website. The provision of links to additional sources of information and the support for shared decision making were also strong plus-points. Areas highlighted for improvement were descriptions of available treatments, the associated risks and benefits of these treatments and their effects on overall quality of life for AIS patients and their families.

It is impossible to control or regulate the health information presented on the Internet but some Websites are more credible than others. The implications are that healthcare professionals should accept responsibility for checking that the Websites they recommend provide contemporary and credible information.

As stated previously, the key factors of the 'Expert Patient Programme' (DOH 2001) are knowledge and patient education to support people living with long term conditions in the self-management of their condition. The results of this study highlight the fact that significant improvements need to be made in this area of patient provision. If we reconsider the five core self-management skills of the expert patient, the overall results of this study suggest that AIS patients and their families in

the UK do not feel confident and in control of their lives. There is some evidence to show that service users can manage their condition and its treatment in partnership with health care professionals though this aspect still needs to be improved. The general lack of knowledge and understanding within this group however makes it unlikely that effective communication with health professionals is currently occurring and it is unclear if patients and their carers are given the opportunity for and/or are willing to share responsibility for treatment.

The poor knowledge of service users also makes it unlikely that service users are realistic about the impact of their disease on themselves and their family. It is also unclear to what extent patients and their carers utilise their skills and knowledge to lead full lives. This is an area of research which has to date not yet been fully investigated within the literature. Improving the knowledge base and educating patients with AIS and their carers, as well as ensuring that they have pertinent information for their age and stage of disease progression is crucial to support the aims of the expert patient programme and support the empowerment of patients.

As stated previously in over 80% of cases patients and their carers reported the curve was in excess of 30 degrees when first diagnosed and supports the results Fazal & Edgar (2006) found, where 56% of patients first presented with a curve greater than 40 degrees Cobb. This means that a significant number of patients are beyond the normal threshold for the prescription of conservative management techniques. It is commonly reported in a number of other health conditions that early diagnosis and treatment can lead to the most favourable outcomes. It may therefore be suggested that screening and educational programmes such as school

screening and programmes for increasing public awareness of scoliosis to promote earlier diagnosis and treatment may be beneficial in the field of scoliosis. This would allow patients the choice of having conservative treatment when the curve is smaller and increase the likelihood of successful treatment.

GPs need to be provided with increased education to correctly diagnose patients without delay to enable the patients to access treatment when their curve is still small. In the United States school screening is legislated in more than half of states and it is compulsory in some other countries such as Japan, Greece, Malta and a number of other countries. In 1984 the American Association of Orthopaedic Surgeons (AAOS) and Scoliosis Research Society (SRS) endorsed the concept of scoliosis school screening (Richards and Vitale 1984) that allowed for early detection of scoliosis for those whose deformities may have gone unnoticed. This Endorsement is based on the assumption that *“early detection in those children at risk for worsening would lead to the implementation of non-operative treatment that would have a positive impact on the long term natural history of this disorder”*.

Study limitations

Response rates were low across some aspects of the study. For example, only 47% (14/30) scoliosis consultants responded to the survey sent to them regarding patient information needs. Also, the survey for patients and families placed on the SAUK Website had attracted 22 responses at the time of the publication of this report. These low response rates have the potential to introduce bias into the study. This is particularly pertinent with the consultant survey as more than half of the UK scoliosis consultants did not respond.

With regard to the patient and carer survey, it could be argued that only people with strong views will respond to such surveys and therefore more balanced views will not be presented in the study. While this is a valid criticism, it was important to hear the voices of those who had opinions and wanted to critique information provision. The responses that were elicited have made a valuable contribution to the study and have informed the study recommendations.

Researchers using the DISCERN tool, which was used to evaluate the validity and credibility of health information websites, showed varying levels of agreement in some aspects of the scoring systems. Good levels of inter-rater agreement had been demonstrated in a previous study (Charnock *et al.* 1999). This is most notable on the overall rating of the SAUK website. This is possibly because the interpretation for meeting the criteria of the questions is highly subjective and subsequently open to variability.

Although these limitations are acknowledged, these do not detract from the importance of the study findings. Each of the components of the study tell the same story, that the quality and range of information for patients with scoliosis and their families needs to be strengthened.

Recommendations

Patients and their families have a need for timely and pertinent information about scoliosis. Patients travel along a diagnosis trajectory which can be a stressful and very anxious time for them and their families. It is therefore recommended that information should be made available at the very beginning of this trajectory, which could be argued occurs at school at the age of 10 years old when children and their families need to be made aware of the condition and how to check for it. It is recommended that patients and their families should be made aware of the condition even before diagnosis, through leaflets at GP practices and at school. A standard information pack should be developed that comprises information on the medical aspects of the condition, diagnosis, possible treatment options and frequently asked questions. The pack should also contain references to pertinent websites and where to access help. The pack should also contain the web site address of SAUK where they can get any questions answered and be put in touch with other service users in their area.

Many patients and their families do not know the signs and symptoms of scoliosis. This can contribute to late diagnosis. It is therefore recommended that ways of increasing the public awareness of AIS in schools should be considered. This could include the annual distribution of leaflets to children from the ages of 10-13 year old similar to the approach adopted in Australia where a national self detection programme is implemented. Alternatives to this could include annual talks given to schools by teenagers with AIS or by SAUK.

It is also recommended that GP practices could be used to raise public awareness of AIS. This could include methods such as posting information about AIS on walls of GP practices and making information leaflets available. This should include basic information about AIS and simple ways of detecting the condition

Currently approximately 50% of patients surveyed for this study had a curve of over 40 degrees when they were referred to hospital. Conservative management was not an option for these patients. Therefore it is recommended that the national scoliosis screening committee review their national recommendations and guidelines on school screening, with a view to either reintroducing school screening or initiating a national self help programme that would empower patients and allow them to access early treatment.

AIS affects a broad age group. Consequently, the information needs of these patients are disparate. Information materials designed for the purpose of informing and educating patients should be tailored to suit different levels of understanding. It is therefore recommended that the information packs should be age-appropriate. For example, information could be tailored specifically for: older children (10-12); younger teenagers (13-14); older teenagers (15-16); and young adults (17-18 and above).

Previous research has shown that patients who are exposed to an amalgamation of written and verbal advice have an increased capability to recall the information than those who were given verbal advice only. Clinicians therefore need to ensure that

patients and their families receive jargon free written information that is appropriate for the patients needs to supplement that which is given verbally in the consultation.

Information packs should contain information on the medical aspects of the condition. In addition it should include information on psycho-social and emotional issues from the patient and from the family's perspectives. For example, it should include information on body image, sexuality and quality of life issues. Other important aspects include, patient and family stories, caring for someone with scoliosis, parental guilt and how to access counselling and other support services. It is suggested that consultants consider referral to either a mental health nurse or clinical psychologist to address any psychological issues which may lead to further problems such as eating disorders in the short term and osteoporosis in the long term.

Information packs should contain a core set of information about the condition with additional supplementary information (leaflets) being added as appropriate for the needs of each patient and their family.

Information packs need to be reviewed annually to ensure they reflect the best available research evidence and incorporate any recent developments such as the effectiveness of scoliosis-specific exercise on mild scoliosis, for which there is now some research evidence. (A Cochrane review on the effectiveness of exercise for scoliosis, co-authored by Dr Bettany-Saltikov, is due to be published shortly).

SAUK website plays a valuable role in information provision for patients and families. The SAUK forum is well regarded and it is recommended that it should continue.

SAUK should consider ways of making the forum more freely available as currently patients need to register before they can contribute to the forum. SAUK should consider the addition of making available on their web-site an area for patients to email any queries and receive personalised responses. This has been found to be helpful, especially for teenagers who may not be willing to talk to someone over the phone.

Consultants need to speak to patients and their parents in jargon free language as much as possible to ensure that patients and their carers understand what is being said to them. A multidisciplinary team approach needs to be promoted in the diagnosis stage. It is therefore recommended that scoliosis clinics should consider employing a specialist nurse with knowledge of the psychological issues relating to scoliosis, to address any questions that service users have during the clinic appointment.

It is recommended that each hospital scoliosis clinic has its own dedicated web site where patients and their carers can ask questions relating to their specific condition.

Patients and their parents should be offered local opportunities to meet and talk with other scoliosis patients and their families in the area.

Young patients with scoliosis strongly recommended that publications need to be easy to read, informative and pictorial as well as providing links for specific advice on a variety of issues relating to scoliosis. These should be distributed throughout hospitals/specialist centres.

More information on scoliosis-specific exercises (for which evidence is now available in the literature) as well as holistic therapies should be made available for those with curves that are just beginning, as much of the current information deals only with surgery.

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Appendix 1: Interview schedule for parents and children

To identify the main information needs of patients and their families at the point of first diagnosis of scoliosis in the hospital clinic.											
Background	Interview questions										
Introduction This is where I/we will remind participants of who we are and the nature of the research and to address ethical issues	Here I/we will introduce myself/ourselves and let them know that I /we are conducting a service evaluation on behalf of the BSRF on the needs of teenagers at the point of first diagnosis. Thank the participants for agreeing to be interviewed. Remind them of the information sheet that they have already received, including arrangements around confidentiality and anonymity. Give a brief description of the research. Check participants are ok with recording interview. Discuss consent and assent forms –participants to sign. Remind participants that they can withdraw at any time until the point of data analysis which will be on (up to 24 hours from the interview).										
Demographics Gaining background information about participant that will help in the analysis	Researcher/s to write down information relating to the age of patient, gender and spinal curvature angle. Time since first diagnosis.										
Introductory phase	<p>The interview will start off with trying to elicit the service-users/parents general experience and /or thoughts.</p> <p><i>How would you describe your experiences on being told you had scoliosis/ or that your child had scoliosis?</i></p> <p>Rationale: This is an introductory question that starts the discussion and should encourage participants to respond to the research topic in an open and candid way.</p>										
Main body of interview	<p><i>Prompt questions: What sorts of things did you first want to know about your scoliosis?</i></p> <p>Depending on the issues raised, for instance, issues related to the prognosis of scoliosis, issues to do with cosmesis, issues to do with their social life or issues to do with their treatment options for instance service users/parents will be prompted as follows:</p> <p>1. <i>What was your specific need?</i> 2. <i>What information did you get?</i> 3. <i>Was the information written or verbal?</i> 4. <i>Could you understand it?</i> 5. <i>Were you satisfied? Yes/no and why?</i></p>										
Concluding questions	<p>For each issue raised above the service users will be asked: “Overall how would you rate the information (relating to this specific issue) that you were provided with? They will then be asked to tick the relevant box below:</p> <table><tr><td><input type="checkbox"/></td><td><input type="checkbox"/></td><td><input type="checkbox"/></td><td><input type="checkbox"/></td><td><input type="checkbox"/></td></tr><tr><td>Very Good</td><td>Good</td><td>No opinion</td><td>poor</td><td>Very poor</td></tr></table>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very Good	Good	No opinion	poor	Very poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
Very Good	Good	No opinion	poor	Very poor							

	<p><i>Could you say more about why you gave it that rating?</i></p> <p><i>And finally they will be asked “what do you think would help improve the information that could be provided?”</i></p> <p>Rationale: These are specifying questions that ask participants to provide precise, detailed, explicit, definite and unambiguous information. Using a scale to rate their satisfaction with the information provided using [numerical data?] that is easy to analyse combined with qualitative data to explain the meaning.</p>
<p>Closure Enables participants to prioritise the issues discussed and provides an opportunity to discuss any issues not already discussed.</p>	<p><i>Was there any other information that you would have liked to have been given? Is there anything else that you want to discuss that has not come up? Have I covered everything?</i></p> <p>Thank you for contributing.</p>

Appendix 2: AIS Information Needs

Welcome

You are invited to participate in our survey which is being carried out as part of a service evaluation investigating the information needs of people with adolescent idiopathic scoliosis and their families. The survey may be completed by the person with scoliosis alone (if aged 16 years or older) or the person with scoliosis together with their parent/carer.

Your participation in this study is completely voluntary. Due to the anonymous nature of the information sent kindly note that once the survey is submitted you will not be able to withdraw from the study.

It is very important for us to learn your opinions in order that we may make recommendations for service improvements. Your survey responses will be anonymous and confidential. You will not be identified. Results of the study will be stored on a password protected computer and paper copies kept in a locked filing cabinet at Teesside University. Following the completion of the research study, results will be stored for up to 5 years and then shredded.

The survey is being carried out by Mr S. Wellburn and Dr J. Bettany-Saltikov both of Teesside University.

Teesside University
School of Health and Social Care
Middlesbrough
TS1 3BA

If you have questions at any time about the survey or the procedures the researcher may be contacted using the contact us link at the top of the page.

Continue >

AIS Information Needs

Main Survey Page

This survey is divided into two sections. The first section consists of general questions about you. The second section consists of questions to help us understand your information needs.

Some of the questions have a **more info** button attached. This is to explain what is required from the question.

General questions about you

This section will be used to gather data about you and your condition.

1. Who is completing this survey?

☐

Person with scoliosis (must be aged 16 years or over)

☐

Person with scoliosis together with their parent/carer

2. How old were you/your child when first referred to the hospital for scoliosis?

3. Is the person with scoliosis?

☐

Male

☐

Female

4. Please enter the first letters of your postcode?

5. Who first identified that there may be a problem? (Please do not enter their name)

6. How long is it since you/your child had the first referral appointment at the hospital?

- ☐ 0-6 months
- ☐ Up to 1 year
- ☐ Up to 2 years
- ☐ Up to 3 years
- ☐ More than 3 years

7. What type of curve were you/your child diagnosed with?

- ☐ Thoracic
- ☐ Lumbar
- ☐ Thoracolumbar
- ☐ Double-major

8. How many degrees was the curve at the first referral?

- ☐ 10-19
- ☐ 20-29
- ☐ 30-39
- ☐ 40-50
- ☐ More than 50

Main questions

The following questions are aimed at understanding your information needs when you were diagnosed with scoliosis.

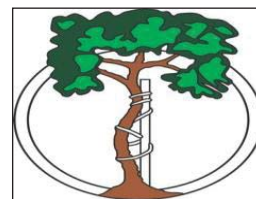
9. How would you describe your feelings on being told you/your child had scoliosis?
(select all that apply)

- ☐ Upset
- ☐ Devastated
- ☐ Annoyed
- ☐ Nervous
- ☐ Anxious
- ☐ Worried

☐ Confused

☐ Other (*please specify*):

Appendix 3: Consultant survey



BSRF

SURVEY

An evaluation of the information needs of people with idiopathic adolescent scoliosis at the point of first diagnosis

The purpose of this study is to determine what information your scoliosis unit currently provides to patients and their families at the point of first diagnosis of scoliosis in the hospital clinic. You are being asked if you would like to participate in this study. Participation and sending documents is voluntary and you can choose to do either or both. By completing the survey you are indicating your consent to participate in the study. Once you have filled in the survey could you please return it in the stamped addressed envelope provided?

All information obtained is anonymous and confidential and will only be disclosed in group format. Due to the anonymous nature of the information sent kindly note that once you post the survey, you cannot withdraw from the study. All completed surveys will be kept in a locked filing cabinet in the researcher's office at the University of Teesside. Following completion of the research study, results will be archived for up to 5 years and then shredded. This form should take approximately 5-10 minutes to complete.

If you have any questions or would like to know the results from this study please do not hesitate to contact me on:

Dr.Josette Bettany-Saltikov

University of Teesside
School of Health
Middlesbrough
TS1 3BA
Tel:01642-384985
e-mail: j.b.saltikov@tees.ac.uk

1. What are the most common questions asked by patients when you first speak to them about their diagnosis of adolescent idiopathic scoliosis? Please list up to 5 questions.

one

Two

Three	<input type="text"/>
Four	<input type="text"/>
Five	<input type="text"/>

2. What are the most common questions asked by parents/carers when you first speak to them about their child's diagnosis of adolescent idiopathic scoliosis? Please list up to five questions.

One	<input type="text"/>
Two	<input type="text"/>
Three	<input type="text"/>
Four	<input type="text"/>
Five	<input type="text"/>

3. Are adolescents with idiopathic scoliosis and/or their parents given any written information? If no go to question 7.

- ☐ Yes
- ☐ No

4. What are the most important topics that the information aims to cover? Please list up to five.

1	<input type="text"/>
2	<input type="text"/>
3	<input type="text"/>
4	<input type="text"/>
5	<input type="text"/>

5. Who has written the information that is given out? Please tick all that apply.

- ☐ You?
- ☐ NHS?
- ☐ Scoliosis Association UK (SAUK) ?
- ☐ other

6. How do people with a diagnosis of adolescent idiopathic scoliosis and their parent/carers get hold of the written information? Please tick and/or make any comments on all that apply.

A member of staff gives them the written information

Written information is available in the hospital for them to pick up if they want.

Other. please specify

7. Are patients and their families referred to any web sites (this can include web sites specific to scoliosis or web sites about general aspects of health and well being).

☐ Yes

☐ No

8. If yes please specify

9. Is there anything else that you think would be useful for us to know, about giving information to people diagnosed with adolescent idiopathic scoliosis and their parent/carers, when you first speak to them about the diagnosis?
